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Explaining how medical doctors learn about and understand the approach to the end-of-life in the workplace

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“Whenever the illness is too strong for the available remedies, the physician surely must not expect that it can be overcome by medicine … to attempt futile treatment is to display an ignorance that is allied to madness”

Hippocrates (cited in Reiser et al., 1977)

Declaration

I, Dr Shaun Peter Qureshi, declare that I have composed this thesis and that it is my own work. This thesis (nor any of the work contained herein) has not been submitted for any other degree or professional qualification.

I was assisted to a limited extent in specific aspects of the conduct of this work and this is clearly indicated in the text:

- Ms. Avril Dewar (indicated as *AD*) assisted with the conduct of the literature search (described in detail in Chapter 3);
- Dr Neill Storrar (indicated as *NS*) independently analysed primary data generated through semi-structured interviews for the purposes of triangulation. Dr Storrar's analysis was separate from my analysis, was discarded following this exercise, and is not included in this thesis in any form (described in detail in Chapter 4, section 4.3.1).

These assistants did not contribute to my analysis and findings, discussion of findings or conclusions, nor construction of this thesis.

Signed,

Contents

Lists of Tables and Figures

Abbreviations

Abbreviations are defined in the text. They are also listed here for reference:

ACP	Anticipatory Care Plan
AD	Avril Dewar
AS	Activity System
ASA	Activity Systems Analysis
AT	Activity Theory
BMA	British Medical Association
CHAT	Cultural Historical Activity Theory
CPR	Cardio-pulmonary Resuscitation
CR	Critical Realism
DNACPR	Do Not Attempt Cardio-pulmonary Resuscitation
EOLC	End of Life Care
FY1/2	Foundation Year 1 or 2 (Foundation Doctor in their first/second year)
GMC	General Medical Council
HDU	High Dependency Unit
ITU	Intensive Care Unit
IV	Intravenous
LLC	Life Limiting Condition
NICE	National Institute for Health and Care Excellence
NS	Neill Storrar
OOH	Out of Hours
PPOC	Preferred Place of Care
PPOD	Preferred Place of Death
QCA	Qualitative Content Analysis
SSM	Scoping Study Methodology
TA	Thematic Analysis
TLC	Tender Loving Care

Acknowledgements

During the process of carrying out this work and constructing this thesis, it has been both challenging and rewarding to conceive this research, and undertake every stage of it until completion. Furthermore, as I have moved from a background of practicing clinical medicine into medical education research, the process has involved developing myself into a researcher, teaching myself how to design, conduct and analyse research from first principles, and a paradigm shift in how I consider science.

I am therefore thankful to the knowledgeable and experienced academic minds who have shared their wisdom with me and helped me in my development along the way. Particular thanks go to Marshall Dozier, Health Sciences Librarian, University of Edinburgh, for her insights into literature searching which was helpful for the study contained in Chapter 3. Others who have met with me to share their experiences and insights into research include (but are not limited to) Dr David Jeffries, University of Edinburgh; Dr Hamish McLeod, University of Edinburgh; Dr Tim Fawns, University of Edinburgh; Dr Joanna Bowden, University of Edinburgh; Dr Jo Hockley, University of Edinburgh; Professor Robin Taylor, University of Edinburgh; Professor Susan Jamieson, University of Glasgow; Professor Lindsay Pope, University of Glasgow; Professor Jen Cleland, University of Aberdeen; Dr Paula Rowland, University of Toronto; Dr Fiona Webster, University of Toronto; Dr Sarah Yardley, University College London; Professor Karen Forbes, University of Bristol.

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Abstract

Background

For patients approaching the end-of-life, treatments with life-prolonging intent can be futile, wasteful, and harmful. Equally, harm may be caused by prematurely treating patients as if they are dying. In order to provide a high standard of care, and align with clinical guidance, doctors must appropriately discern when a patient is approaching the end-of-life. This thesis takes the necessary and novel step of developing an explanation for how medical doctors learn about and understand the approach to the end-of-life in the workplace.

Research aims

1. To examine how the approach to the end-of-life is conceptualised by medical doctors;
2. To explore experiences and understandings of doctors learning to care for patients at the approach to the end-of-life, including factors which provide barriers to learning;
3. To develop a theoretical explanation of the learning of doctors about the approach to the end-of-life.

Methodology and methods

Taking a critical realist ontological position, this thesis considers what causal mechanisms influence doctors learning about and understanding the approach to the end-of-life. Data were generated through complementary methods:

- Scoping study and qualitative content analysis (QCA) of medical literature (2006-2016) to examine established conceptions about the approach to the end-of-life among UK medical doctors;
- Thematic analysis (TA) of data from semi-structured interviews with newly graduated (foundation) doctors to explore development of understandings of the approach to the end-of-life, and influences on this development and learning;
- Examination of the findings through the lens of a socio-material epistemological framework – Cultural Historical Activity Theory (CHAT) – to theorise how interacting factors influence the learner/practitioner in a complex environment.

Results

QCA of two hundred and sixty-nine included documents identified that there is no single shared understanding of the approach to the end-of-life among doctors. TA of data from fifteen interviews with foundation doctors indicates that care of the patient approaching the end-of-life is a central aspect of their role and is learned about after leaving medical school, beginning practice, becoming integrated into the workplace. Both the literature and interview data indicate the approach to the end-of-life is not understood as a discrete entity but is constructed dynamically in relation to the patient, their disease, potential treatments and implications of these treatments, from the perspective of the practicing doctor. CHAT allowed for consideration of this practice-based learning as systems of activity, and identification of where contradictions within and between each activity system act as barriers to learning and practice.

Discussion and conclusions

The results have significant implications for educators and policy makers: understandings of the approach to the end-of-life are not gained in advance of practice (i.e. in medical schools). Instead, understandings are dynamically constructed by doctors in their practice. Improving the doctor's workplace by overcoming tensions and challenges identified in this thesis should be focuses for intervention to improve learning and care for these patients in the future.

Lay Summary

Recent healthcare events have demonstrated that it can be futile, wasteful, and harmful for doctors to attempt to prolong the lives of patients who are dying. However, some cases have also shown that patients may be harmed if they are prematurely treated as if they are dying. It is challenging for doctors to discern when a patient is approaching the end-of-life, but necessary to do so in order to make judicious decisions about appropriate patient care. This thesis takes the necessary and novel step of developing an explanation for how practicing medical doctors learn about and understand the approach to the end-of-life in the workplace.

In order to address its aims, this research adopted different streams of investigation. Two hundred and sixty-seven documents written for medical doctors in the UK were examined to investigate how the approach to the end-of-life is discussed and conceptualised by doctors. Interviews were conducted with fifteen UK doctors within their first two years of practice (foundation doctors) and further analysis was conducted to explore how they experienced and understood the approach to the end-of-life, including factors which provide barriers to learning. In order to consolidate the findings and lead to a useful theoretical explanation of doctors' learning and understanding, the research incorporated an established theory of learning (Cultural Historical Activity Theory or CHAT) which allows the learner to be considered as a practitioner within a complex workplace environment.

The results indicate there is no single shared understanding of the approach to the end-of-life among doctors. The most junior UK doctors, i.e. foundation doctors, have an important role in care of patients approaching the end-of-life in the hospital, however learning about this care happens after leaving their undergraduate training at university medical schools, and begins when they start practicing as doctors. Becoming integrated in the workplace greatly influences their learning. Both the documents and interview data indicate that understanding the approach to the end-of-life is not straightforward. Doctors draw upon and interact with various aspects of the workplace to come to such an understanding. Using CHAT as a framework allowed for consideration of where tensions in the workplace lie and how these can act as barriers to learning and practice.

The results have important messages for workforce planners and medical educators. Understandings of the approach to the end-of-life are not gained in advance of practice (i.e. in medical schools) and there is not one single way of understanding this which applies to all patients and contexts. Instead, understandings are developed by doctors in their practice, and are dynamic and subjective. Workplace factors may facilitate or hinder the doctor in developing their understandings and in providing adequate care. Improving the doctor's workplace by overcoming tensions and challenges identified in this thesis should be focuses for intervention to improve learning and care for these patients in the future.

Output as a postgraduate research student

During my enrolment as a postgraduate research student I have authored the following **peer-reviewed journal articles:**

- N. Kwankajonwong, C. Ongprakobkul, S.P. Qureshi, P. Watanatada, S. Thanprasertsuk, S. Bongsebandhu-phubhakdi. Attitude but not self-evaluated knowledge correlates with academic performance in physiology in Thai medical students, 2019. Advances in Physiology Education. 43: 324-331.
- S.P. Qureshi, K. Rankin. Junior-to-junior research interviews as method for clinical practitioner-researchers. 2019. Advances in Medical Education and Practice. 10: 127-137.*
- S.P. Qureshi, K. Rankin, N. Storrar, M. Freeman. Preparation for Making Clinical Referrals, 2018. The Clinical Teacher. 15:1-5.
- N. Wongjarupong, D. Niyomnaitham, P. Vilaisaktipakorn, T. Suksiriworaboot, S.P. Qureshi, S. Bongsebandhu-phubhakdi. Interactive Laboratory Classes (ILCs) Enhance Neurophysiological Knowledge in Thai Medical Students, 2018. Advances in Physiology Education. 42(1):140-145.
- S,P, Qureshi, H. Jones, J. Adamson, O. Ogundipe. Ageing Simulation for Promoting Empathy in Medical Students, 2017. BMJ Simulation Technology and Enhanced Learning.3:79-81.

**This article directly relates to methods I have adopted in this thesis and the publication is included here as Appendix 7*.

During my enrolment as a postgraduate research student I have authored the following **peer-reviewed published abstracts:**

- S.P. Qureshi, A. Dewar. Describing treatment aims for patients approaching the end-of-life: mapping concepts from a scoping study of the medical literature (abstract), 2018. BMJ Supportive and Palliative Care; 8(S1):A17.
- S.P. Qureshi. Challenges to recognising the dying patient in acute care – perceptions of senior and newly graduated Scottish doctors (abstract), 2018. BMJ Supportive and Palliative Care; 8(S1):A7.

During my enrolment as a postgraduate research student I have given the following oral presentations:

International conferences:

12th Dec 2018	Exploring newly graduated doctors' workplace learning about the approach to the end-of-life using Cultural Historical Activity Theory – Pre-Seminar of 8th International Seminar of the Palliative Care Research Centre (International Palliative Care research conference), Edinburgh, UK
24th Aug 2018	How to make a long story short: the challenge of consolidating various threads of a study of learning about the approach to the end of life among newly graduated doctors – Rogano Meeting, Basel, Switzerland
31st Aug 2017	Learning about the limitations of medicine – Rogano Meeting, Helsinki, Finland
17th Aug 2017	Why are we doing this? New doctors' perceptions of investigations and treatments for dying patients – Preventing Overdiagnosis Conference, Quebec, Canada
21st June 2017	For want of a better word: developing a taxonomy for the teaching and training of end-of-life care from a scoping review of UK medical literature – Association for the Study of Medical Education Annual Scientific Meeting, Exeter, UK
21st May 2017	I know how you feel: aging simulation for promoting empathy in Medical Students – International Clinical Skills Conference, Prato, Italy
7th July 2016	Preparation for treating life limiting illness: beyond specialist palliative medicine – Association for the Study of Medical Education Annual Scientific Meeting, Belfast, UK

National conferences:

26th September 2019	Newly graduated doctors learning about the approach to the end of life in the workplace – Strathcarron Conference, Edinburgh, UK
15th March 2018	Challenges to recognising the dying patient in acute care: perceptions of senior and newly graduated Scottish doctors – Association for Palliative Medicine, Bournemouth, UK
5th May 2017	Not all Sunshine and Rainbows: Findings from a qualitative study of newly qualified Scottish doctors learning about 'Do Not Attempt CPR' Decisions - Scottish Medical Education Conference, Edinburgh, UK
19th Oct 2016	The patients who don't get better: Preliminary findings from a qualitative medical education study of Scottish foundation doctors – Medical Research Symposium for Doctors and Students in Training, Royal College of Physicians of Edinburgh, Edinburgh, UK

Invited presentations:

6th June 2019	Knowing-in-practice: newly graduated doctors learning about the approach to the end-of-life in the workplace – Centre for Healthcare Education Research and Innovation, University of Aberdeen, Aberdeen, UK
17th January 2018	Learning about the limitations of medicine… Research in Progress (webinar) – MSc Clinical Education, University of Edinburgh, Edinburgh, UK

During my enrolment as a postgraduate research student I have presented the following **academic posters:**

15th March 2018	Describing treatment aims for patients approaching the end-of-life: mapping concepts from a scoping study of the medical literature – Association for Palliative Medicine Annual Scientific Meeting, Bournemouth, UK
28th Aug 2017	Handovers, hierarchy, and why they matter for Scottish medical trainees learning about end-of-life care: findings from a qualitative medical education study – Association for Medical Education in Europe Annual Scientific Meeting, Helsinki, Finland

During my enrolment as a postgraduate research student I have obtained the following **competitive research grants:**

2017	Learning to recognise dying: Exploring barriers to effective education and supervision of doctors-in-training – Association for the Study of Medical Education (ASME) Small Grant (£461.50)
2016	Learning About the Limitations of Medicine: Exploring Barriers to Effective Learning – University of Edinburgh Principal's Teaching Award Scheme (PTAS) (£4924.00)

During my enrolment as a postgraduate research student I have obtained the following **competitive travel grants:**

2018	William Dickson Travel Fund – University of Edinburgh (£110)
2018	University of Edinburgh Go Abroad! Fund (£350)
2018	Page Bursary – University of Edinburgh (£250)
2017	Page Bursary – University of Edinburgh (£250)

Other achievements during my enrolment as a postgraduate research student:

September 2019	Selected as one of the top 3 abstracts submitted to the Strathcarron Conference (2019), and so selected as one of only 3 oral presentations (over poster presentation)
May 2017	Selected as one of the top 5 abstracts submitted to the Scottish Medical Education Conference (2017), and so selected as one of only 5 oral presentations (over poster presentation)
Oct 2016	Selected as one of the top 5 abstracts submitted to the Royal College of Physicians of Edinburgh Medical Research Symposium for Doctors and Students in Training (2017), and so selected as one of only 5 oral presentations (over poster presentation)

1. Introduction and background

1.1. Introduction

This thesis addresses the overall aim of developing an explanation of how medical doctors learn about and understand patients approaching the end-of-life. This chapter will firstly explain what I mean by the approach to the end-of-life in this context. I will discuss the background literature and explain why this is a necessary focus of study, and explain my personal motivation. Lastly, this chapter will justify the studies I have undertaken, and introduce the structure of thesis.

1.2. The approach to the end-of-life

The concept which, for the purposes of this thesis, I term the *approach to the end-of-life*, is one which relates to an area of debate which is highly relevant to the medical practitioners, and patients, as I will explain. In order to be clear about what is meant by this concept, it is helpful to consider death itself.

Most people can agree when someone has died[1]. Healthcare practitioners diagnose life as extinct, normally associated with the cessation of spontaneous breathing, circulation, cardiac activity, and reflexes (Department of Health, 2019). Equally, it is obvious that all people who are currently alive will die at some time. Most people in the United Kingdom die in hospital or another healthcare setting. These patients may be found across healthcare sites and commonly patients' lives end in acute general hospitals (Gomes, Higginson and Saunders, 2008). However, from neither societal

[1] Although not universally, e.g. Kitzinger and Kitzinger's (2014) work on 'the in between'.

nor medical viewpoints are living people generally considered to be dying. It is only in certain contexts that people are perceived as near the end of their lives. In healthcare, this is reflected in the emphasis on end-of-life care as a discrete mode of care, different from other care (Shipman et al., 2008; National Institute for Health and Care Excellence (NICE), 2011).

Modern medical literature places importance on doctors providing high quality care for patients at the 'end-of-life' (Brooks, 2014; NICE, 2015). Furthermore, guidelines for providing good quality end-of-life care increasingly emphasise anticipating the patient's end-of-life in advance (Mullick, et al., 2013; The Scottish Government, 2015; Finucane et al., 2017). Literature advises decision-making with cognisance of the length of the patient's remaining life (Detering et al., 2010; Lightbody et al., 2018) suggesting doctors should identify patients who will reach the end-of-life soon, i.e. approaching the end-of-life.

This raises the question of what it means to be approaching the end-of-life and by what means the end-of-life is anticipated. The constituent factors which inform the identification of approaching the end-of-life are not universally agreed upon (Jünger et al., 2012), and, for the same patient, different doctors may reach different conclusions about whether a patient is dying (Greene, 2013; Gallagher et al., 2015; Willmott et al., 2016). It is how the approach to the end-of-life is considered by medical doctors, and what influences these considerations, that is inconsistent and still unclear.

This exploration is not one of purely academic interest; it is highly relevant to patient care. Discourse in healthcare literature and more generally indicates that the space which precedes a patient's death is of importance to doctors and patients. Providing

good quality end-of-life care is an important aspect of contemporary medical care (The Scottish Government, 2008; General Medical Council (GMC), 2010). Reports of poor-quality end-of-life care have led to criticism of doctors, including perceived failures to identify and plan for patients approaching the end-of-life. For example, the Parliamentary and Health Ombudsman report 'Dying without dignity' (2014) was critical of ongoing investigations for patients who died soon after. They deemed these patients should have been recognised as dying, with different care decisions being made. Additionally, the performance of cardio-pulmonary resuscitation (CPR) – a life-prolonging intervention designed to increase survival in cases of cardiac arrest (Hayes, 2013) – should be considered in a judicious manner. Its use in patients who are dying is considered invasive, undignified and futile. Failure to anticipate dying has led to dying patients receiving CPR which is perceived as poor-quality care of the dying (National Confidential Enquiry into Patient Outcome and Death, 2012).

Making appropriate decisions about investigations and treatments *not* to perform has also been highlighted as a health resource issue. There is pressure on health services, including the United Kingdom National Health Service (NHS), to economise with limited resources in the context of an ageing population. Thoughtful clinical decision-making may reduce wastage of resources by not providing futile interventions. For example, in Scotland, the Government's report 'Realistic Medicine' (2015) declared doctors should not overuse medical interventions in a system with constrained resources. In Lanarkshire, Scotland, Lightbody et al (2018) demonstrated that treatment escalation plans and *Do Not Attempt Cardiopulmonary Resuscitation* (DNACPR) decisions could reduce non-beneficiary interventions. Internationally, the 'Choosing Wisely' (American Board of Internal Medicine, 2019) campaign publicises the importance of doctors only performing interventions that are

truly necessary and will not cause patient harm. Discerning which treatments will not be beneficial, and therefore waste resources, requires an understanding of when the patient is likely to die regardless of medical intervention.

Conversely, instances when doctors *have* deemed that patients were approaching the end-of-life have also led to criticism. At such times, the criticism was that doctors should have continued to pursue life-prolonging treatment for the patient e.g. for doctors not to attempt to revive a patient with CPR has led to criticism of doctors inappropriately accepting the patient's death (Heslop et al., 2013). Furthermore, widespread controversy over the Liverpool Care Pathway, a now defunct hospital care plan for dying patients in the United Kingdom, included perceptions that doctors were inappropriately labelling patients as dying and failing to re-evaluate patient treatment appropriately. There was criticism that doctors did not assess patients dynamically and realise when the patient's condition changed so that they were not in fact dying (Neuberger, 2013). This led to the Liverpool Care Pathway being withdrawn and hospitals reconsidering their management of end-of-life care (Seymour and Clark, 2018).

These events indicate that it is important for doctors to understand when a patient is approaching the end-of-life. Failure to do so can lead to patients receiving healthcare interventions which are not appropriate for dying patients. However, considering a patient as approaching the end-of-life in some instances may be a mistake, leading to harm if they are inappropriately treated as if they are dying. These understandings are therefore crucial to patient care, but complex and challenging to establish. It is important to investigate doctors' understanding of the approach to end-of-life, what influences these understandings, and how they are developed and learned about.

Throughout the thesis I will refer to this part of patient care as the approach to end-of-life, which I acknowledge is vague. This is to allow the meaning(s) of the approach to end-of life – i.e. the part that comes before dying – to be openly investigated and considered, whatever it may be, without pre-supposing how this might be understood. As this thesis will go on to argue, there are varied subjective ways in which this is conceptualised. Clearly, the *approach to the end-of-life* is itself a subjective conceptualisation, however it is used for want of a better term to represent the area under study.

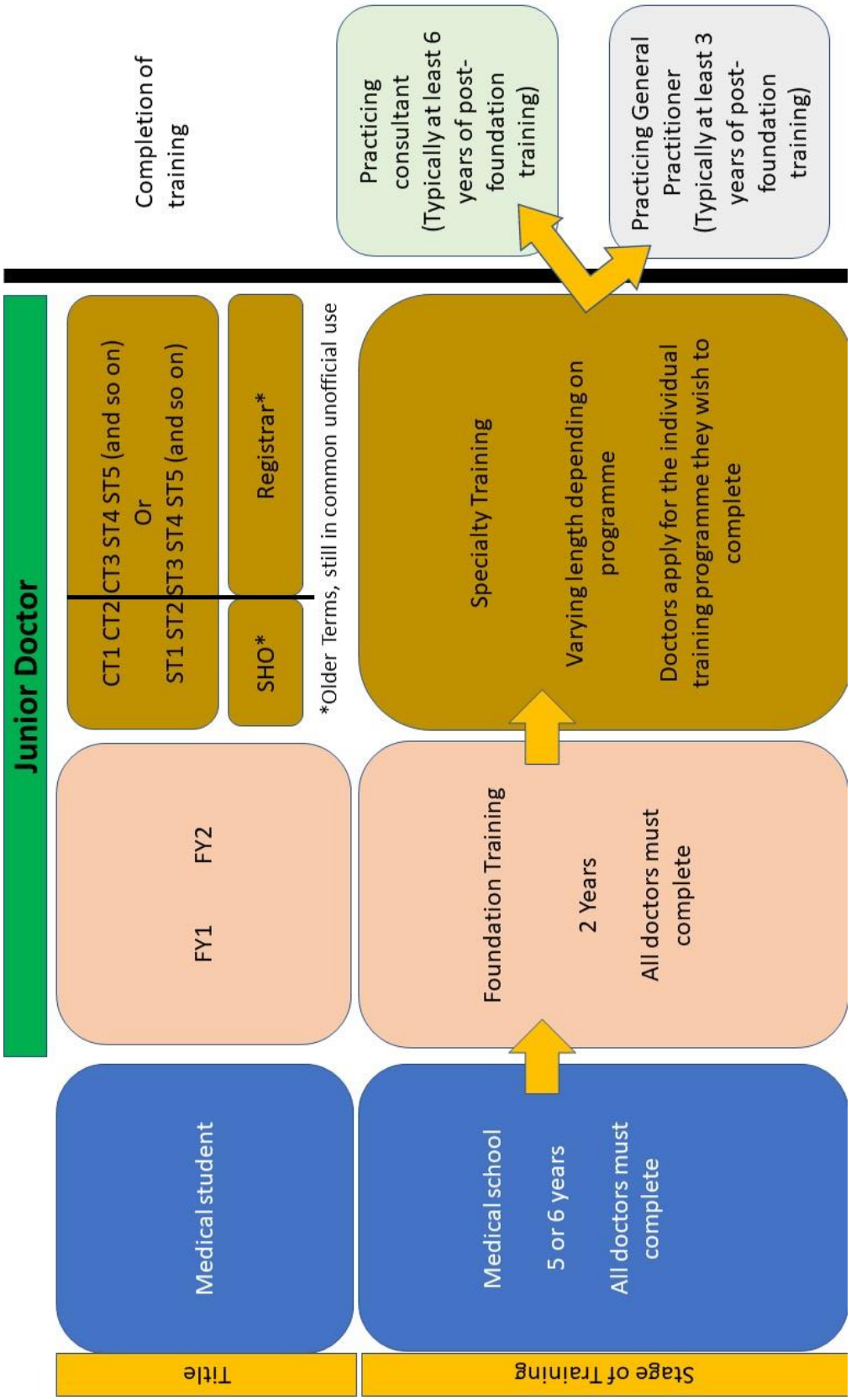
1.3. Medical education for the end-of-life

In my primary data generation (Chapters 4 and 5), I have focused on the learning of newly graduated medical doctors in the general hospital setting. This section will explain why newly graduated doctors have purposefully been selected as the subject of study.

In the United Kingdom, doctors graduate and begin work after completing five or six years as medical students undertaking an undergraduate medical degree (or four years if entering a postgraduate programme such as ScotGEM (University of St Andrews, 2020)). After this, newly graduated doctors enter a 2-year 'Foundation' postgraduate training programme which consists of work across a variety of specialties in a junior capacity. Following foundation training, doctors can enter 3–8 years of advanced or specialist training before becoming certified as consultants or general practitioners. During this period, doctors are employed in the National Health Service and undergo learning in the workplace (British Medical Association (BMA), 2017b). In the UK 'junior doctor' is a common term used to describe working doctors

undergoing postgraduate training who are not yet fully trained specialty consultants or general practitioners (BMA, 2017a). This is represented below in Figure 1.

Figure 1. Summary of UK training system for medical doctors, adapted from BMA (2017b)



Caring for patients who die in hospitals is part of the role of newly graduated doctors. It has been identified that the *most junior* of junior doctors (foundation doctors) spend most time with dying patients (Gibbins et al., 2010). However, it is an aspect of care for which these doctors may feel poorly prepared. They may not realise that this is a major focus of the work of the junior doctor until they begin work (Gibbins, et al., 2011). Previous authors have found that junior doctors are not prepared for providing end-of-life care prior to practice, including difficulties managing distress and feeling sufficiently confident (Bowden et al., 2013; Price and Schofield, 2015). I therefore anticipated that understandings of the approach to the end-of-life are also heavily influenced after beginning practice.

Efforts have been made to incorporate end-of-life care into undergraduate medical curricula and to facilitate corresponding teaching and learning at medical schools (Field and Wee, 2002; Linklater, et al., 2014; Boland et al., 2019). However, as described above, it is insufficient for a doctor to know good practice for patients already identified as dying. This means that despite developing a high standard of clinical knowledge and technical skills – including care of the dying – newly graduated medical doctors may not have developed understandings of the approach to end-of-life prior to starting work.

This thesis includes exploration of how these understandings are developed. Foundation doctors are at the threshold of practice, having just completed undergraduate training and now starting their career as working doctors. They will undergo learning in the workplace, including learning about care of patients approaching the end-of-life in hospital. By studying doctors at this stage, valuable insights can be gained on influences on the development of understandings of the approach to the end-of-life: the influences of medical school, of having started work,

and how starting work has changed pre-existing understandings which may have been developed in medical school.

1.4. Workplace influences for junior doctors

As this thesis explores the workplace learning of doctors, and incorporates research investigating the effects of the workplace on this, it is necessary to understand the current cultural context of junior doctors' work. During the time I conducted this work, the climate of UK medical training presented challenges for doctors, trainers and workforce planners. Many doctors feel that the working environment is worsening for trainees (Royal Medical Benevolant Fund, 2017). Proposed changes to work patterns have led to reports of junior doctors feeling undervalued. Well-publicised disputes regarding changes to the junior doctor contract negotiations in England resulted in junior doctor strikes in 2016. These brought these issues to the attention of the public, and the disputes provided an outlet for the pre-existing dissatisfaction of junior doctors (Goddard, 2016).

Recent incidents have led to perceptions of junior doctors being vulnerable within a wider organisation. In one case, Dr Chris Day was removed from his training and rendered unemployed by Health Education England after he raised concerns about patient safety in his workplace (Cooper, 2018). Lack of whistleblowing freedom for junior doctors is detrimental to patient care (Francis, 2015) but the case of Dr Day demonstrated lack of structural protection for junior doctors to raise concerns. In another example, a specialist trainee in paediatrics, Dr Hadiza Bawa-Garba, was found guilty of manslaughter by gross negligence following mistakes in treatment of a patient who died under her care. Dr Bawa-Garba was removed from the register

of licensed medical practitioners by the General Medical Council. Many doctors raised concerns about perceived draconian treatment of Dr Bawa-Garba who had been blamed individually despite multiple wider organisational influences on her actions (Rimmer, 2018; Clarke, 2018). Such cases demonstrate systemic factors can negatively influence junior doctors in the workplace.

It is widely recognised that junior doctors are discontented. Morale is poor among junior doctors and mental health problems are prevalent (Van Hamel and Jenner, 2015). This has been brought into sharp relief following well-publicised cases of junior doctor suicides (Ross, 2016; Hemmings, 2018). Furthermore, attrition from the workforce is common, with many doctors discontinuing postgraduate training or leaving practice altogether (UK Foundation Programme Office, 2018). Smith et al (2018) identified contributing reasons for doctors leaving the UK after foundation training, including lack of perceived support, bullying, perceived rigidity of training structure, and changes to junior doctor contracts.

1.5. Personal motivation

My personal views have influenced my decision to undertake this research. My clinical experiences of working in hospitals have led me to appreciate the practical applications of these issues, and that improving education in this area is needed. As a junior doctor, I work as part of a multi-disciplinary team in caring for patients. Recognising when a patient may be approaching the end-of-life is difficult and uncertain, and is not managed in a uniform way. I have experienced occasions when patients deteriorate and die, without the healthcare team (including me)

acknowledging or realising that they are dying. These have been dissatisfying and potentially distressing for the patient, their relatives, and healthcare team, and have made me question established practice.

Current literature is not sufficiently useful to explain or guide the complexities of practice. For example, the principles of anticipatory care planning and palliative care do not necessarily make it easier to discern the correct course of action when working as a doctor, faced with a sick patient in hospital. Furthermore, I believe we should not simply accept that this area is too complex, uncertain and variable to understand. On the contrary, patients can experience harm from lack of adequate understanding. It is necessary to persevere with aiming to reach a deeper and more useful understanding, with the aim of contributing to improved practice. Pursuing this research is therefore vital for practicing good patient care, as well as being of great personal interest.

1.6. Gaps in current knowledge

This thesis aims to establish how doctors understand, and learn about, the approach to the end-of-life. This addresses gaps in current knowledge as this aim is not met effectively by existing literature. Firstly, no previous research takes the same inductive, comprehensive approach to exploring the breadth of understandings of patients approaching the end-of-life. Previous studies have explored understandings of pre-determined concepts related to palliative care (Pastrana et al., 2008; Jünger et al., 2012; Bausewein and Higginson, 2012; Ewert, et al., 2016). Moreover, previous authors have identified that challenges to providing end-of-life care include recognising dying (Redman et al., 2017). This thesis focuses in detail on aspects of

understanding the approach to the end-of-life, i.e. wider than one conception such as recognising dying. My work examines a breadth of conceptions of the approach to the end-of-life without pre-defining them, so that conceptions are generated inductively from the investigation.

Secondly, this thesis takes the necessary step of examining how entering practice as a doctor affects development of these understandings. Existing literature has identified challenges for doctors – including junior doctors – understanding palliative care (Hanratty et al., 2006, Luthy et al., 2009; Gibbins et al., 2010) and lack of preparation for care of the dying as medical students (Gibbins, et al., 2011; Bowden et al., 2013; Price and Schofield, 2015). I have gone further by exploring how doctors making the change from medical student to practicing doctor experience patients approaching the end-of-life, and how this change influences learning about this part of patient care.

Furthermore, this work is the first to effectively explore and connect the difficulties faced in working lives of UK junior doctors and the challenges of providing care for patients approaching the end-of-life. Previous authors have identified cognitive influences on UK doctors' decision-making in care of the dying (Charman and Esterhuizen, 2016; Taylor et al., 2017). This contrasts to the workplace learning perspective of this thesis which considers knowledge about end-of-life care as constructed through interaction with workplace factors. Canadian research has investigated how the organisation of the hospital often does not facilitate good care of patients approaching the end-of-life (Chan, 2014; Chan et al., 2017). However, this thesis takes the valuable next step of exploring the influences of the workplace on learning and understanding the approach to the end-of-life in the UK context.

1.7. Justification of study

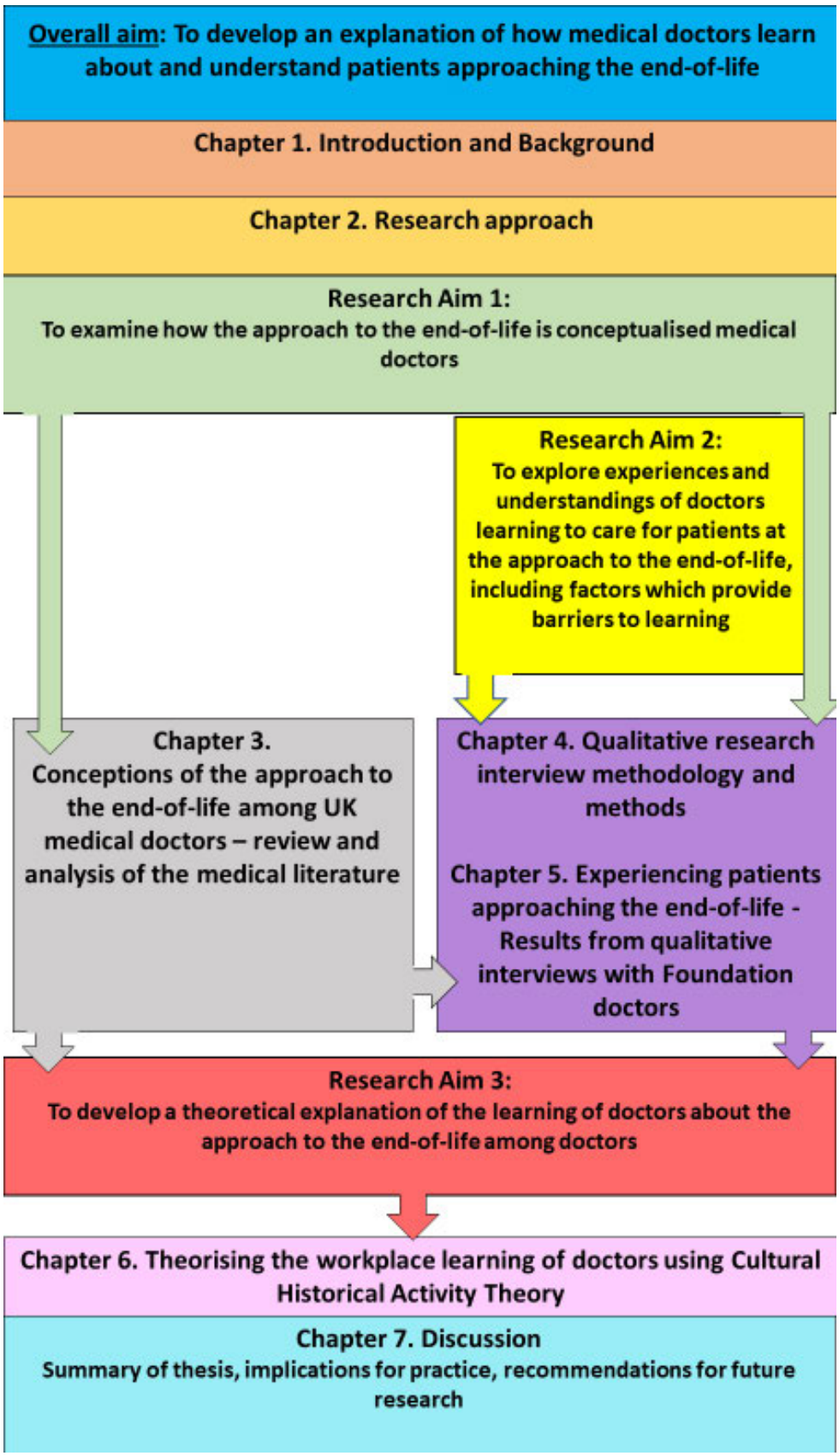
This chapter has justified why this thesis is necessary: doctors do not normally treat their patients as if they are dying, but must appropriately discern when a patient is going to die so that patients are not inappropriately treated in ways which may be painful and undignified, and wasteful of resources. Equally, doctors should not inappropriately or prematurely treat patients as if they are going to die. For the purposes of this thesis, I use term the *approach to the end-of-life* for this concept that doctors must be able to adequately understand and discern in their patients. Previous literature has not clearly established how doctors understand, and learn to understand, the approach to the end-of-life, therefore this thesis will take the necessary step of developing an explanation for this. This will incorporate considering the learning of doctors in the workplace learning in hospital, with awareness that the workplace provides a challenging environment for doctors-in-training, with systemic factors which affect their learning and practice. I have illustrated that this research addresses an aim which is not currently met by existing literature. By carrying out this research, improved understandings can lead to improved patient care.

In the next chapter, I will discuss the methodological and philosophical considerations which underpin this thesis. This will include a discussion of the educational perspective I take, how this corresponds with workplace learning, and the theoretical framework I incorporate to reach a theoretical explanation of doctors' learning. Following this, I will build on these discussions to present my research aims and methodological strategy to meet these aims.

1.8. Summary of thesis structure

Figure 2 displays the structure of this thesis, illustrating how the chapters correspond with the established aims. Figure 2 is also included as a *pull-out* appendix which may be referred to while reading each section of this thesis in order to be cognisant of the overall structure while doing so (see Appendix 1).

Figure 2. Summary of structure of this thesis.



2. Research approach

2.1. Introduction

This chapter will explain the methodological considerations which underlie this thesis and define the scope and aims of the thesis. I will explain the philosophical and educational paradigms on which the research is based and their implications for research. I will then present my aims, explain my methodological strategy to meeting these aims, and discuss the theoretical framework I incorporate. I will discuss the importance of research trustworthiness, and how these considerations have influenced my process. These include issues of reflexivity, and correspondingly, I will describe my identity as the researcher and axiological position. This chapter will allow the reader to understand the perspectives from which my research has been formulated, analysed and interpreted.

2.2. Ontology and epistemology

2.2.1. Paradigms

Research questions which may be asked (and answered) are dependent on what the scientist believes is possible to know. Differing scientific paradigms (Kuhn, 1962) inform the conduct of research, and more fundamentally, what should be studied. Beliefs and presumptions of what counts as knowledge, and how these can be come to be known, are described as epistemology. Epistemological beliefs, in turn, are

dependent on what the scientist believes about the world in which they exist, i.e. ontology (Crotty, 1998).

Clinical and social science research is often conducted from a realist ontological perspective: a belief that there is an existence which is independent of human perception and experience (Maxwell, 2010). Research within this paradigm seeks to establish observable relationships and rules which can be verified via testing. Interpretation of data is framed as objective, therefore the influence of humans on conduct and analysis of research should be limited. Realist research traditionally takes a positivist epistemology, i.e. they are interested in findings which can be empirically verified. Positivists consider anything that can be known (or is worth knowing) as measurable. They would not consider subjective perceptions, emotions, or opinions as useful data (Cruickshank, 2012). Contemporary researchers, however, more commonly accept that although the ideal would be for all theory to be verifiable, that idealised research cannot always exist. The dominant epistemology has moved from certainty (positivism) to probability (post-positivism) (Illing, 2014).

In contrast, qualitative research does not involve measurements and uses a variety of methods to investigate how individuals interpret and make sense of their experiences and the world (Varpio, Martimianakis and Mylopoulos, 2015). Researchers who use a qualitative approach often do so within an interpretivist ontological paradigm. Interpretivism rejects the concept that reality can be understood as independent of human perception. Reality must be understood from what is interpreted by individuals. Therefore, human interpretation is the basis by which reality can be known and the means through which science should proceed (Robson and McCartan, 2016). Qualitative methods may be more suitable for examining complexities of society and context (Greenbank, 2003). Many researchers

who undertake qualitative research engage in social constructivist epistemologies, i.e. take on an epistemological position that reality is not fixed and has no underlying essential structure, therefore meanings conveyed between humans in social interaction represent the production of knowledge. It is not the *raison d'etre* of social constructivist research to claim that findings of individual studies are necessarily generalisable to other settings (van Brussel and Carpentier, 2014). Validity, as far as can be applied to quantitative research, does not apply to qualitative research, and instead the trustworthiness of research is often considered. As will be explained in section 2.5, separate quality criteria for qualitative research have been established.

2.2.2. Critical realism

Although I agree with some principles of both realism and interpretivism, neither can satisfactorily explain my position. I accept there is a reality separate to human perception; however, I reject the notion that anything that can be known must be measured, or that human perception (including perceptions of researchers) can be objective. The philosophy which underpins this thesis aligns better with yet another ontological and epistemological position: critical realism (CR). Like realism, within CR there is held to be objective reality which exists beyond individual experience, and it is answers about the world outside perceptions that scientists should ultimately seek. However, CR rejects the notion that epistemology is equal to ontology as an *epistemic fallacy*, i.e. that everything that can be known is the same as everything that exists. CR has been argued to reconcile ontological realism with epistemological relativism and judgemental rationality (Bhaskar and Lawson, 1998).

CR was originally conceived by Roy Bhaskar as a cross between *transcendental realism* and *critical naturalism*. Transcendental realism is the view that nature is real, and science exists to understand it. For scientific investigation, the object of investigation must have real, manipulable, internal mechanisms that manifest to produce outcomes, which exist independently of their identification (Bhaskar and Lawson, 1998; Nunez, 2014). This contrasts to classical positivist traditions of research which do not differentiate between what exists and what can be known to exist. Critical naturalism argues that the realist model of science applies to both the physical and social worlds, although these worlds are fundamentally different. It is therefore necessary to adopt social scientific methods to investigate the mechanisms producing social events, with a recognition that these are in a more dynamic state than the physical world. This contrasts with a realistic empiricist view of static constant-conjunctions, i.e. predictable, identified laws which can show that one thing causes an occurrence (Collier, 1994).

Ascertaining individual perceptions and knowledge is not a useful final goal. Instead we should consider the causal mechanisms which exist. However, critical realists accept, like many interpretivists, that research will always be subjective. Qualitative and quantitative research should be well-constructed, but can only provide an approximation of reality (Mcevoy and Richards, 2006; Edwards, et al., 2014b).

2.2.2.1. Knowledge and knowing

Within CR, reality is conceptualised as stratified, based on Bhaskar's idea of three depths of existence: empirical, actual and real. These are summarised in Figure 3 and Table 1.

Figure 3. Critical Realist stratification of reality, adapted from Bhaskar (1975)

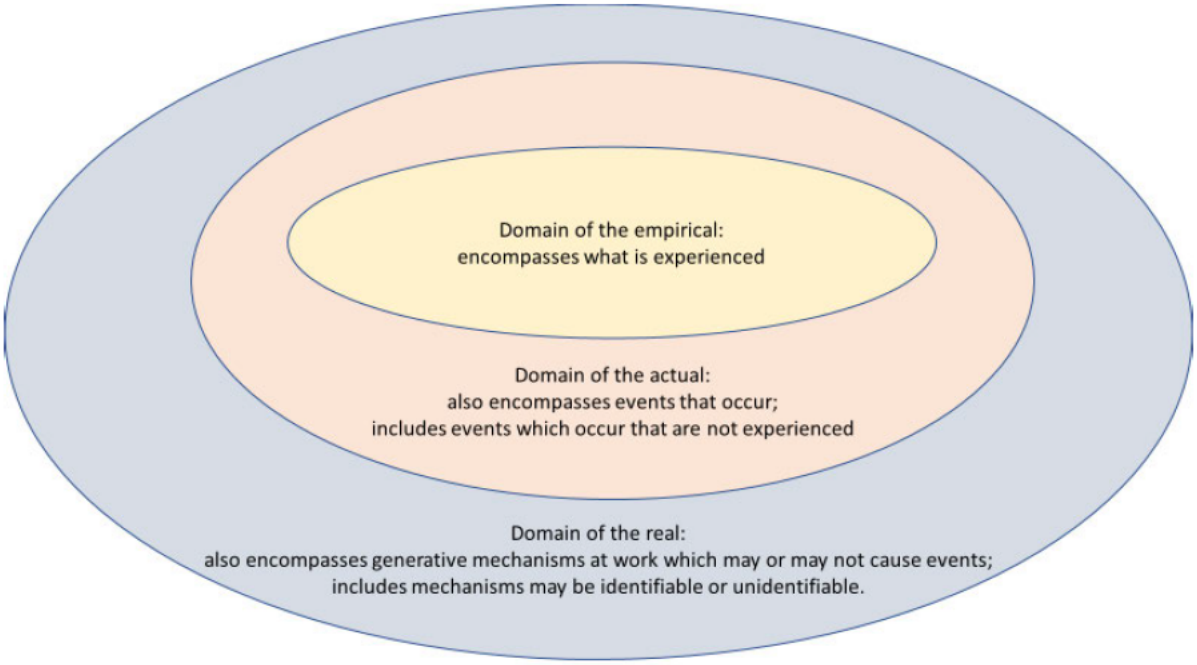


Table 1. CR elaboration of stratification of reality, adapted from Bhaskar (2017)

	Domain of the real	Domain of the actual	Domain of the empirical
Mechanisms	✔		
Events	✔	✔	
Experiences	✔	✔	✔

Generative mechanisms exist regardless of whether they are known. Mechanisms may create an event or may not. Social events are caused by interactions of social structure and agential causal power (Elder-Vass, 2010b). Causal powers interact, leading to actual events occurring, which may be interpreted subjectively as empirical experience. What is understood and experienced is only a small part of what exists (Bhaskar, 2017). In order to understand why events occur, it is necessary to identify the powers at work and how they interact with one another (Collier, 1994).

CR differentiates between open and closed systems. The social world can be described as an open system – systems with many interacting factors which prevent the course of events and experiences from being predicted (Edwards, et al., 2014b). Viewing this through Bhaskar's theory, this can be explained in the domain of the real: there are many factors which act as tendencies for events to be empirically manifest (i.e. in the domain of the actual), in situations where no counteracting mechanisms act. It is these mechanisms which critical realists seek to examine without the assumption that manifestations of mechanisms are predictable. This contrasts with the positivist views of research which aims to study closed systems, i.e. to isolate one process to study in order to identify individual causal laws. Bhaskar (1987, p35) described an experiment in terms of studying a single mechanism in isolation, "free from the interfering flux of the open world". CR research takes the view that no one mechanism determines the whole result. Furthermore, if an outcome of a relationship is not observed or does not occur, it does not mean those mechanisms do not exist. Denial of the existence of mechanisms because an outcome is not observed is described as the *fallacy of actualism* (Nunez, 2014).

Bhaskar (1987) described his wish that studying the world will allow people to identify negative influences and improve the human condition. Identified mechanisms could

be targets for work towards human emancipation. As will be described below (2.5.3), it was important to me that this work would lead to positive changes. By determining structures and mechanisms which affect human lives and prevent humans from flourishing, it is hoped we can eradicate these obstacles.

2.2.2.2. Methodological possibilities

CR differentiates between what is known and is possible to know (epistemology) and what exists (ontology). In open systems, multiple mechanisms operate. The goal of CR research is to find wider causal mechanisms and explanations, rather than simple, isolated relationships between cause and effect. It is necessary then to make use of the methodologies, methods and theories which will be most helpful to establishing what is real. However, research will inevitably be imperfect as it is carried out by fallible, subjective humans.

CR allows for epistemological – and therefore, methodological – flexibility. The CR researcher is not bounded to any one research tradition (Edwards, et al., 2014b). In this thesis, I investigate workplace learning of doctors learning about the approach to the end-of-life. I have utilised qualitative methods, although they are normally associated with an interpretivist ontological position. In doing so, it is important to be conscious of limitations, and that even robust research can only provide an approximation of reality. The research presented here does not explore perceptions of learners as end in itself, but as a means to understand factors influence their learning in practice. I sought to investigate the experiences and perceptions of subjects learning within complex open systems, therefore it was appropriate for me to adopt qualitative methods and methodologies in pursuing this aim.

2.3. Socio-material educational perspective

The hospital is recognised as an important site of learning among medical students and doctors. This occurs as students undertake rotations in different departments as part of their medical degree, and as junior doctors contribute to patient care while undertaking postgraduate training. This may be structured – e.g. mentoring (Brown, et al., 1989) – or unstructured, everyday experience of work (Billett, 2001b).

Different ways of conceptualising workplace learning have been described: learning for work; learning at work; learning through work. In medical education, one means of broadly categorising workplace learning theories is differentiating individual learning theories (e.g. behavioural or cognitive) from distributed learning theories (e.g. social learning theories) (Morris and Blaney, 2011). Much medical learning and teaching takes an individualist perspective by focusing on preparation for practice: aiming to improve knowledge and skills in advance of commencement of work as a doctor. The assumption is of an *acquisitive* perspective of learning, i.e. one where the learner must acquire proficiencies they need for the workplace, and that improving education should involve doctors being more prepared for work (Zukas and Kilminster, 2014). There are also perspectives within medical education which conceives learning as *socio-cultural*, focusing on knowledge construction through interactions between living beings and cultural influences on this (Fenwick, 2010b; Liljedahl, 2018). From such perspectives, the workplaces are not only environments where people can learn (Billett, 1992) but indeed there is no separation between participation in work and learning (Lave, 2011): practice is learned by practicing (Dornan, 2012; Kahlke, et al., 2019).

Throughout this thesis, I take a *socio-material* perspective of learning. This stands in contrast to the dualist (mind v. body) view assumed in the acquisitive perspective of learning, and instead views professional learning as participational, i.e. without a disparity between 'knowing' and 'doing'. Knowledge is practical, embodied and social: it does not only exist in the mind as a thing to be transmitted from one person to the next. Socio-materiality also goes beyond socio-cultural theory: understanding the relationship between individuals and the social world is important for understanding learning, but this includes the vital role of matter and materials in how entities relate to each other and learn (Fenwick, 2010a; Zukas and Kilminster, 2014). This aligns with Gheradi's (2012) description of 'knowing-in-practice': knowledge is not a body of knowledge but an activity that is both individual and collective. Knowledge emerges from its own production, grounded in materials in specific contexts. Work is not the application of acquired knowledge, but through work knowledge is used as a resource in the production of further knowledge.

Socio-material research foregrounds the material, unlike other perspectives or methodologies which emphasise human processes (Fenwick, 2010a). The human should therefore not be perceived as divorced from materials in the workplace. This is relevant to medical practice where a variety of tools inform medical practice and design (Fenwick and Nimmo, 2015) and neglecting materials may put patient safety at risk (Bleakley, 2012). There is no single theory of socio-materiality and there are many socio-material apparatuses which may be employed in research (Fenwick and Nimmo, 2015; Fox and Alldred, 2019). Later in this chapter, I will introduce a specific theory, Cultural Historical Activity Theory (CHAT), which provides a framework which aligns to the socio-material perspective, and my critical realist view of reality.

2.4. Research aims and strategy

2.4.1. Research aims

Medical doctors understanding the approach to the end-of-life is vital. I have described the need for this research in Chapter 1. This led to the defining of the overall research aim:

To develop an explanation of how medical doctors learn about and understand patients approaching the end-of-life

In order to meet this aim, it is necessary to consider this in its component parts which will are presented below:

1) To examine how the approach to the end-of-life is conceptualised by medical doctors
2) To explore experiences and understandings of doctors learning to care for patients at the approach to the end-of-life, including factors which provide barriers to learning
3) To develop a theoretical explanation of the learning of doctors about the approach to the end-of-life

The rationale of these aims, and the strategy by which these aims will be met, is described in detail below. How research methodologies correspond with these study aims is summarised the thesis structure shown in Figure 2 /Appendix 1.

2.4.2. Methodological strategy

In pursuing my aims, I employ different complementary qualitative methodologies and methods. Qualitative research is a broad term for research approaches which investigate meanings of phenomena in their natural settings (Liamputtong Rice and Ezzy, 1999; Cleland, 2015). Qualitative research is particularly useful when an exploratory approach is needed, when the subject is complex, and when an understanding of the context is needed (Cresswell, 2007).

Within qualitative research, multiple traditions exist, e.g. ethnography, phenomenology, grounded theory methodology (Robson and McCartan, 2016). The mixing and/or combination of qualitative methodologies to reach a study have been established (Denzin, 2012; Kahlke, 2014; Varpio, Martimianakis and Mylopoulos, 2015). Furthermore, qualitative research approaches which do not strictly correspond to a research tradition have been established (Sandelowski, 2000; Kahlke, 2014).

In Chapter 3, I address Aim 1 through investigation into the conceptualisation of the approach to the end-of-life among medical doctors. This investigation consists of scoping study methodology in order to obtain a broad sample of UK medical literature, and Qualitative Content Analysis (QCA) of the included texts, i.e.

combining qualitative interpretation with a comprehensive literature review. QCA allows analysis of not just the terms in use, but the concepts represented.

In Chapter 5, I present findings from an exploration of workplace experience of newly graduated doctors encountering and learning about the approach to the end-of-life in practice. Participants were foundation doctors: they had recently passed through the threshold from medical school to clinical practice and would be better able to describe their experiences of undergraduate teaching, early practice, and their influences of learning to care for patients approaching the end-of-life, compared with doctors who had been practicing for longer. This addresses study Aims 1 and 2, by examining how the approach to the end-of-life is conceptualised and understood. The methodological process to this study, discussed in detail in Chapter 4, involves data generation through semi-structured interviews with participants, and inductive thematic analysis (TA) in order to identify important meanings across the data.

The findings from these studies are derived through inductive analytical processes and with reference to theories described above (CR, socio-materiality) in interpreting the results. In Chapter 6, I then address aim 3 by further theorising about the findings through the lens of Cultural Historical Activity Theory (CHAT). Theory, defined by Reeves et al (2008) as "an organised, coherent, and systematic articulation of a set of issues that are communicated as a meaningful whole", is useful for qualitative researchers, and multiple ways of incorporating theory are possible (Sandelowski, 1993). I draw upon theory to advance understanding of the phenomena under study. Furthermore, adopting theory fits with CR research which aims to theorise about mechanisms and establish why things come into being. In theorising explanations, it was necessary to adopt further modes of reasoning: abduction and retroduction. These processes add theory to data. Abduction is the process of considering what

mechanisms are at work to explain the empirical events which have been identified. Retroduction is theorising about what the world must be like for the mechanisms to exist (and for others not to exist). Abduction and retroduction may occur as part of the same process. To achieve this, CR allows for incorporation of theoretical frameworks (Edwards, et al., 2014b).

Sandelowski (1993) describes theory as "fitting" the data when it provides a framework for organising the data, when it allows comparison between components easily, and when the meanings of data are not distorted. It was necessary for me to identify theories which would correspond with my CR perspective, workplace learning and socio-materiality. It was apt to therefore consider practice theory: theory which assumes the importance of activity, performance and work in creation of social life, and recognising activity as institutionalised and sustained by material and social relations (Gheradi, 2012; Nicolini, 2012). A practice-based study may alternatively be termed a study of knowing-in-practice, as defined in section 2.3. Practice theory is complementary to critical realism and is useful for studying work and organisation (Gheradi, 2012).

The methodological processes described throughout Chapters 3-5 are not bound to a specific theoretical framework. However, as a researcher I was influenced by my underlying philosophical position, and by the socio-material theories which underpin this work. Therefore, the theoretical aspects discussed in this chapter (CR, socio-materiality, practice theory) were sensitising concepts: they provided a theoretical foundation upon which I developed further interpretations of social phenomena (Bowen, 2006). The exploration of how medical doctors understand the approach to the end-of-life (Chapter 3) also then provided sensitisation for the inductive thematic analysis of interview data with foundation doctors (Chapters 4 and 5). CHAT (a form

of practice theory) was then explicitly adopted as a theoretical framework, the results of which are presented in Chapter 6.

As I will describe below, incorporating CHAT involves further logical processes by adding theory to the data (Edwards, et al., 2014b). Incorporating CHAT allowed me to meet study Aims 3 by providing a framework with which theorise the learning of medical doctors about the approach to the end-of-life, where challenges lie within practice, and how they might be overcome. Furthermore, Yamagata-Lynch (2010) recommends conducting thematic TA alongside utilising CHAT, allowing the TA to be complemented by the structure of CHAT. Such a combination is pre-established in educational research (de Feijter et al., 2011; Archer et al., 2018). Below, I describe CHAT and its usefulness in providing a socio-material framework with which to theorise the factors influencing learning in practice.

2.4.3. Cultural Historical Activity Theory

2.4.3.1. Learning through activity

CHAT is a theoretical perspective originally devised for studying children at play but has been subsequently developed by philosophers interested in learning through practice (Yamagata-Lynch, 2010), especially in complex systems (Engeström, 1987). This built on Marxist notions of work as a social, collective, practical and material human activity (Nicolini, 2012; Johnston and Dornan, 2015). Marx defined necessary elements for an activity to be considered as work: the worker; the material upon which s/he works; the instrument used to carry out the work; the actions carried out as a

worker; the goal toward which s/he works; the product of her/his work. Work is always carried out in relation to other people (Marx 1867 cited in Marx 2013). Within CHAT, organisations are sites of ideological struggle between those who control the means of production and labourers whose work and knowledge are exploited (Fenwick, 2010a).

CHAT stands in contrast to many strands of scientific thinking which are based in Cartesian dualism (the concept of the separation of the mind and the body) (Johnston and Dornan, 2015). CHAT does not consider the individual and environment separately, and postulates that human consciousness is co-created through participation in activity (Vygotsky, 1978; Yamagata-Lynch, 2010). Within CHAT, learning and development occur through practice and the fundamental unit of the life of an organism is not individual behaviour but activity which is collective and requires communication and interaction between people (Hedegaard, et al., 1999).

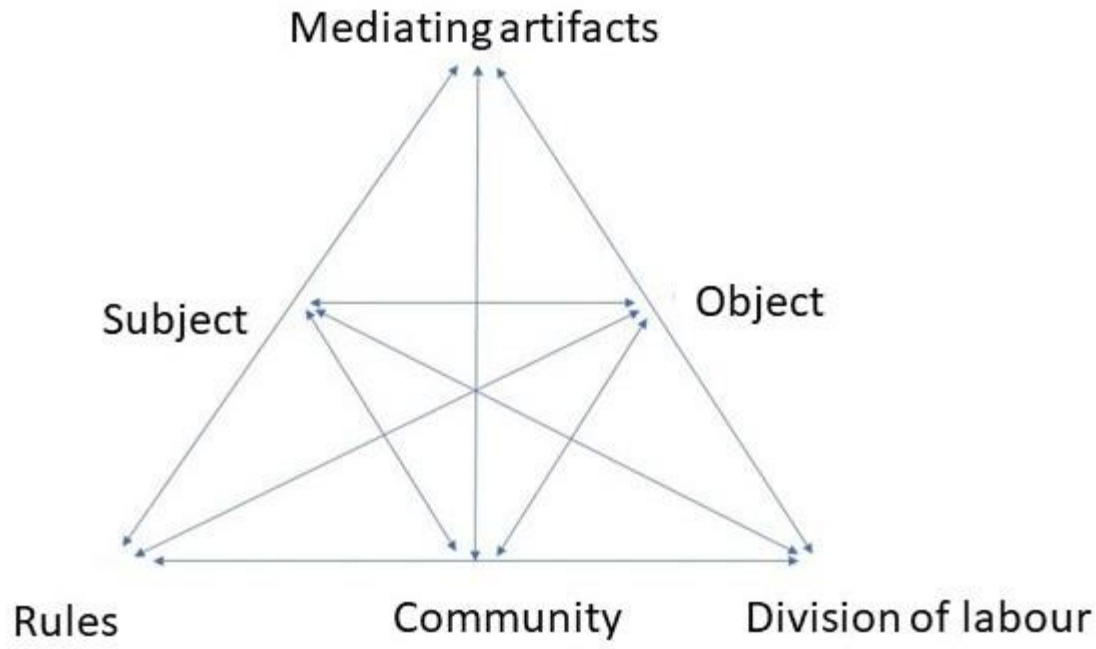
This system forms the basic unit of analysis in CHAT – the activity system (AS) – and is graphically represented by a series of triangle diagrams. The AS consists of a subject aiming to bring about a change (object). The object of an activity may be material or intangible. Humans do not react directly to their environment, but always in some way mediated by artefacts (Nicolini, 2012). Within an AS, the subject may be an individual, group or organisation (Yamagata-Lynch, 2010).

One major developer of CHAT, Leontiev, conceptualised distinctions between operation, action and activity (Leontiev, 1978; Yamagata-Lynch, 2010):

- Operations are the most basic level of human action. These are individual component parts of an action which are part of larger activities, and they take on meaning in the context of that activity.
- Actions are goal-directed and composed of simple operations. Actions occur over a relatively short period of time with a defined beginning and end. Actions tend to be individually focused and provide means for individuals to participate in activity.
- Activities are object-orientated, consist of multiple actions, and are collectively focused. Activities encompass collective and collaborative actions which are the steps taken by subjects in participating in the activity.

Operations, actions and activities require cultural and historical understanding in order to acquire meaning. For example, on a busy acute medical receiving unit one might see a junior doctor pick up a needle and syringe (an operation). This is one step in the process of taking blood from a patient (the action). The junior doctor is one member of the team working collaboratively to do the work of admitting unwell patients to the hospital, diagnosing them and providing them with appropriate care (the activity). Activity as conceptualised by Leontiev is illustrated in Figure 4.

Figure 4. Diagram of the minimum unit of analysis from 2nd generation CHAT adapted from Engeström (1987)



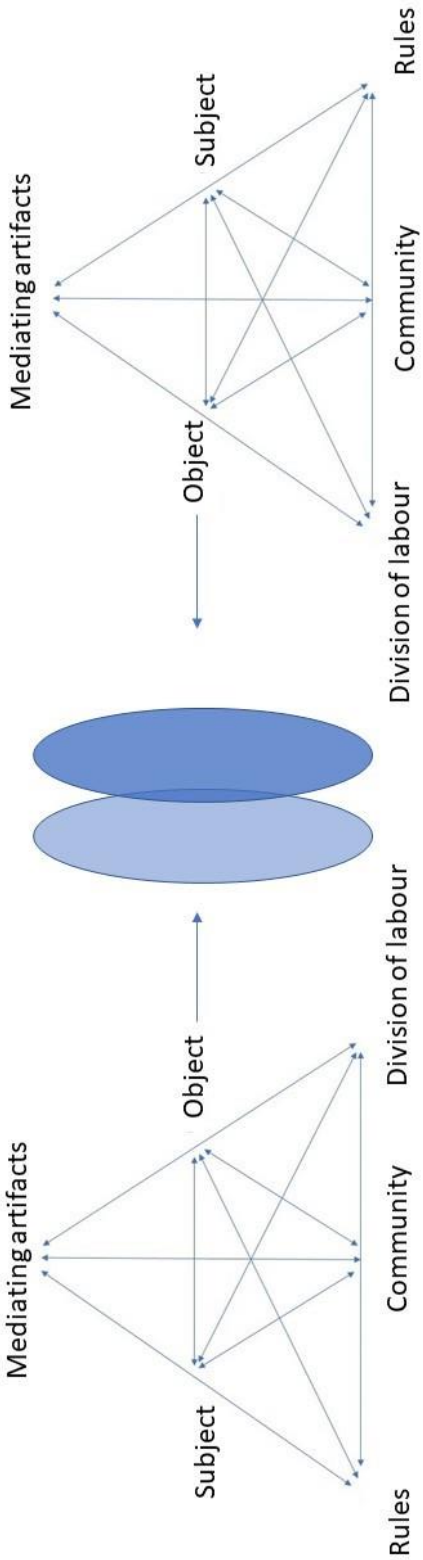
Within the AS, knowledge is co-constructed between the learner and their social world. Learners need to skilfully work within an AS, and with the tools used within the AS (which includes theories and concepts) as part of their practice (Wheelahan, 2007). Within CHAT, the activity cannot be understood only by looking at its individual constituent parts (Nunez, 2014). CHAT emphasises that many social voices are in dialogue with one another (*multi-voicedness*), and each part of the AS influences the others (Johnston and Dornan, 2015).

The centre of control in an AS changes, and there are differing combinations of people and artefacts. There is reliance on actions of others and combinations of people and tasks change constantly. This complexity and interdependence are

referred to as *knotworking* (Engeström, 2001). Knotworking denotes a deeper interdependence than simply forming relations, but that making relations must fixed and long-lasting (or not easily un-formed) through collaboration (Gheradi, 2012). The bidirectional arrows in the diagram represent the dialogic nature of interaction.

Yrjo Engeström has advanced the study of CHAT incorporating not only one bounded AS, but the interactions between neighbouring systems (Engeström, 1987). This emphasises the concept of multi-voicedness (Nicolini, 2012). This conceptualisation of systems under study with CHAT has generally been termed third-generation CHAT (see Figure 5).

Figure 5. Diagram of 3nd generation CHAT, adapted from Engeström (2001)



CHAT is a suitable theory for studying complex learning environments at work, as it views work as constantly changing mix of actors over long periods of time, and widely distributed in space (Engeström, 1987). Furthermore, CHAT allows consideration of how and why an AS occurs in its current form, and how it may be changed in the future to overcome tensions within the system, as will be described below.

2.4.3.2. Development of and within an activity system

The above section has described the AS and the importance of multi-voicedness and knot-working in studying systems using CHAT. This section will describe other central tenets of contemporary CHAT – contradiction, internalisation, externalisation, and learning as expansive transformation (Nunez, 2014). These are necessary for understanding why systems exist in their current form and how they may be changed in the future.

CHAT allows for study of tensions that exists between and within systems. When tensions occur, the socio-material community is not integrated and working harmoniously, and there are multiple conflicts (Nicolini, 2012). Within CHAT, these tensions are called contradictions (de Feijter et al., 2011). Contradictions may occur at different levels (as will be expanded up on in Chapter 6). It is through reflection on contradictions and considering new forms of an activity which overcome contradictions that systems develop (Fichtner, 1999), i.e. undergo expansive transformation. Activity systems occur in their present form because of *historicity*: past events which have influenced them to do so, and how past contradictions have been overcome. In the future, systems will evolve through discovering new ways of doing things, coming from currently un-thought space (Nunez, 2014).

Vygotsky developed the educational idea of the Zone of Proximal Development (ZPD). ZPD represents the space between the actual developmental level of a learner as determined by independent problem solving, and the level of potential development through problem solving under adult guidance or in collaboration with more capable peers (Vygotsky, 1978). Through the lens of CHAT, the ZPD has been incorporated to represent the distance between learners simply learning things by rote without understanding the purpose, and later coming to internalise what the action really means. In other words, within the AS, the subject may know in principle what actions should be carried out, but it is only as the subject becomes familiar with the functioning within the system and the mediated actions they are learning, they start to understand the importance and significance of different aspects of activity (*internalisation*). This can be seen as moving from abstract learning to concrete learning and occurs with influence from teachers and/or the wider community (Engeström, 1987).

Furthermore, through this learning process, subjects will also begin to question why things are done the ways they are (*externalisation*). Over time, subjects identify where the contradictions exist in their activity. By reflecting on these contradictions, expansive learning may occur, i.e. developmental transformations in activity systems (Engeström, 1987). This occurs through moving across ZPDs and creating new ways of carrying out an activity. Expansive learning therefore involves transforming entire activity systems or fields of activity.

Expansive learning leads subjects and activity systems to become qualitatively different (Fichtner, 1999) as contradictions emerge and are resolved (Nicolini, 2012). Ultimately the purpose of studying workplace practice using CHAT is not simply to display the findings using the AS framework, but to identify where the contradictions

lie and how they may be overcome to lead to expansive learning. This therefore allows a CHAT framework to fit well with CR research as will be described below.

2.4.3.3. Critical realism and CHAT

This thesis has taken a CR philosophical perspective and incorporates a socio-material theory (CHAT) in understanding its research. As described above, it is expected within CR research to find a means to theorise about findings, as means of considering the underlying mechanisms at work. In this thesis, I have selected CHAT as a theoretical lens. However, there are significant differences between CR and CHAT: CR is a relatively recent ontological philosophy which emerged from the philosopher of science Bhaskar (1975); AT is a social theory which emerged as a means of understanding social practice.

I have explained that from the CR ontological standpoint, truths about a reality external to human perception exist. It rejects the view that what can be known is the same as what exists, and calls this the 'epistemic fallacy' (Bhaskar and Lawson, 1998). In contrast, traditionally the CHAT perspective is one of knowledge which is constructed in the interactions between subjects in an activity system and mediated by culturally specific artefacts. From this viewpoint, one might argue there is not one single objective reality which can be separated from our interpretation of this. However, I have explained that, although a realist ontology, CR allows for methodological flexibility and reconciles with epistemological relativism. Within CR, embracing a framework which may align with constructivist epistemology – the co-construction of knowledge between subjective individuals – does not undermine the underlying belief that there is an external world which is outside of human perception.

On the contrary, adopting CHAT as an apparatus facilitates theorising the factors which influence the experience of individuals.

Furthermore, there are also many parallels between CR and CHAT, which support the use of CHAT as a theoretical apparatus to be drawn upon in research from a CR perspective (Nunez, 2014). Both CR and CHAT consider the relationship between individual and wider society. They aim to identify underlying causal mechanisms for phenomena, rather than considering only what is experienced (Wheelahan, 2007). Moreover, both reject the search for prediction, seeking instead to discover relationships between influences in the social world rather than constant conjunctions (Sayer, 2000).

In fact, CHAT has been postulated as a means to overcome the structure-agency debate which is long-standing within social research (Johnston and Dornan, 2015). Critical realists like Archer (2003) argue that people exercise free will, but not under conditions of their choosing, meaning that cognisance of the influence of structure on individual behaviour is essential. Social structures are the outcome of past social interactions between past agents which condition the context in which current agents find themselves, and the way in which current agents respond to their context shapes the social structures in which future agents find themselves. This corresponds with CHAT which considers the cultural and historical contexts which have led up to subjects acting the way they do within an AS (Johnston and Dornan, 2015).

CHAT also allows consideration of how practice within a system may be developed in the future in individual and collective experience, through resolution of contradictions (Fichtner, 1999) and contribute to an improved world (Engeström, 1987). Correspondingly, CR is orientated towards establishing the mechanisms

which affect our lives, in order to improve human experience (Bhaskar, 1987). Through CHAT from a CR perspective, the object of investigation can be seen to enable emancipation, and self-emancipation of learners through learning (Nunez, 2014).

2.5. Research trustworthiness

In this section I discuss aspects related to the trustworthiness of the qualitative research. I will discuss issues of research quality and describe who I am as a researcher.

2.5.1. Quality

Within qualitative research, the researcher is integral to every stage of the research process and influences data generation and analysis. In my qualitative research I accept that I am a subjective individual, generating data in interaction with the study material, often in interaction with other subjective humans. Research from a quantitative paradigm has traditional quality criteria against which it is appraised by its *validity*, which does not correspond with qualitative research (Kuper, Lingard and Levinson, 2008). Lincoln and Guba (1985) described alternative criteria for assessing the truth and merit – or *trustworthiness* – of qualitative work, as discussed below. These are broadly analogous to quality criteria for quantitative research (Schwandt, 2007; Mann and MacLeod, 2015) (indicated below with ≈ symbol).

- Credibility (≈internal validity) i.e. the extent to which research has been conducted well so that the findings can be considered “true” in the context of the inquiry. This involves demonstrating that every stage of the research process is aligned, and correct processes have been followed. Within the CR paradigm, truth can never be totally elucidated by research as all human perception is fallible, but it is the aim for the researcher to reach as “true” an approximation of reality as possible through robust research. Throughout my research, I have referred to established methodological resources to guide my conduct and justify my choices. Explanations for unusual and surprising findings have been postulated. Researchers also often employ practical measures to ensure credibility, including triangulation (Mann and MacLeod, 2015). Various definitions of triangulation exist, but in this context, I mean employing another method or tool to examine the same subject matter to increase trustworthiness of findings (Mcevoy and Richards, 2006; Varpio et al., 2017). I am employing combined methodologies and methods to generate both empirical and theoretical findings to support my thesis (see section 2.4.2). The use of triangulation within my primary data collection is discussed in Chapter 4. Credibility of my research can be demonstrated by my justification of the approach with established tools and literature, and triangulation.
- Dependability (≈reliability) i.e. whether results would be consistent if the study would be repeated in the same context (this relates closely to credibility). As I have explained, my CR ontological position means that I believe that multiple generative mechanisms exist in the social world (an open system) (section 2.2.2) which may or may not make events manifest and exist regardless of whether they are perceived. I therefore do not believe that data generation can be reproducible, nor that another researcher would come to the same conclusions as I have.

However, I have provided detailed explanations throughout this thesis in order to explain the choices I have made and what has led to my claims. Another researcher can therefore follow the research process and understand how claims have been reached.

- Transferability (≈generalisability) i.e. the extent to which results can be useful in other contexts. Applying findings across contexts is challenging in all aspects of research, regardless of paradigms (Tolsgaard, 2018). Qualitative researchers may produce results which are unique to the contexts in which studies are conducted. In the case of this research, although I have conducted this research at a site in Scotland, I believe the findings are applicable to other settings: in Chapter 3 I present analysis of a breadth of medical literature from across the UK, and in Chapter 5 I present analysis of interviews with doctors who are completing a national training programme in common with other doctors elsewhere in the UK. I situate the findings in existing literature and discuss how they compare with previous findings from other contexts. The detail in descriptions of my processes will also allow the conclusions to be drawn about the applicability of findings to other settings (Mann and MacLeod, 2015). Ultimately, the work of discerning the transferability of results to one's other context rests with the reader (Liamputtong Rice and Ezzy, 1999).
- Confirmability (≈objectivity) i.e. how neutral the researcher has remained during data generation and analysis. As I have explained, I consider myself a key component in the research process, actively involved in the *generation* of data. This means that I cannot make claims for objectivity. Nevertheless, it is important that data generated, and subsequent analysis, reasonably correspond with the source material and/or meanings of participant subjects. Furthermore, for the

reader to judge the confirmability of this research, it is essential for me to declare my beliefs and assumptions. How these concerns relate to my research are explored later in this chapter.

The research concepts have been presented separately, but processes which ensure trustworthiness are inter-connected. Furthermore, these criteria have faced criticisms. They do not correspond exactly with quantitative conceptions of quality, and it may be reductive to try to make research align with quantitative research to be considered worthwhile (Tuckett, 2005b). Furthermore, being rigorous should not mean removing flexibility and freedom for individualistic interpretation (Sandelowski, 1993).

Maintaining research trustworthiness consists of striking a challenging balance between accepting subjectivity as an inevitable part of qualitative research interpretation and not abandoning objectivity to the extent that findings have no external meaning (Greenbank, 2003). This involves introspection and questioning of the effect of one's self on the generation and interpretation of data. This practice of self-critique and examining one's own prejudices is known as reflexivity (Malterud, 2001). Throughout the research processes presented, I endeavoured to be reflexive by considering how I have affected the research planning, data generation and analysis. Below, I describe aspects of my identity and my values which have influenced these processes. At suitable points throughout the results chapters of this thesis, I will describe how I have maintained reflexivity in response to the findings from the data.

2.5.2. The researcher

I am a junior doctor working in the UK. My experiences as a medical student and junior doctor have led me to consider medical education from a practice-based viewpoint rather than a cognitive one. As a medical student I was diligent: participated in all prescribed teaching and learning activities; studied learning resources outside of classroom time; performed well in assessments. I proceeded from the start of my degree to graduation without difficulty and from the perspective of the medical school, I was a good student. One might assume that such a good student may then be in a good position to begin practice as a competent junior doctor. In fact, I found upon starting work there was a great deal about practicing as a doctor which I did not know. Although my clinical knowledge was adequate, I often felt helpless and uncertain within a system that I did not understand. I felt that what I had learned at medical school – although necessary – only provided the foundation for practice as a doctor, and the important things to learn were learned by doing the job. Thankfully, through the process of postgraduate training I learned to practice as a competent doctor. Even now, as a junior doctor who periodically moves between different workplaces as part of my prescribed training programmes, I always have a period of unease and steep learning because of differing ways of organising the workplace, meaning I must repeatedly learn to integrate and find my place within a new professional team. Although the technical medical aspects may be the same or similar, practice as a doctor is dynamic and varied. Learning to function a junior doctor has involved learning to adapt to these different workplaces and interacting with people in different ways.

Throughout my clinical work I have been particularly interested in care of patients approaching the end-of-life in the general hospital setting. I have been influenced by my own experiences of caring for patients approaching the end-of-life and my view of the important role that junior doctors play at these times. In my view, organisational and interpersonal factors, as well as clinical uncertainty, affect practice of care for these patients. I am pursuing a career in specialist Palliative Medicine (year 6 of postgraduate training, year 2 of higher training with palliative medicine). I have an interest in supporting colleagues from other specialties with end-of-life care.

My belief that the learning of junior doctors is situated within a system affected by multiple overlapping practical and interpersonal factors has led to me to my CR and socio-material research perspectives. In the context of this research, I am a practitioner-researcher i.e. undertaking systematic research relevant to my job (Robson, 2002). As I am a junior doctor carrying out this research about junior doctors, it has a specific dimension. For example, during the questions asked, the information divulged and the nature of the communication throughout the semi-structured interviews would be different had they been conducted by someone else.

2.5.3. Axiology

If CR research should be working towards allowing humans to have a better existence, this necessitates an ethical standpoint on the part of the researcher (Edwards, et al., 2014b). I agree with Stewart and Martinez (2011, cited in Morrison and Sacchetto, 2018) that research should be moral and amplify “the voices of the excluded”. It would be misleading for me to claim this research is value-free

(Greenbank, 2003), and the principle of *axiology* tells us that the values of the researchers influence the choices made (Zaidi and Larsen, 2018). Therefore, here I briefly present some details of my axiological position, i.e. values which have influenced me as a research.

It is important that this research abides by my intention:

- To carry out research which is academically rigorous;
- To generate knowledge which will contribute to improving the work experiences and their learning for doctors;
- To generate knowledge that will facilitate the care of patients approaching the end-of-life;
- To represent the valuable role played by doctors in healthcare;
- To be respectful to doctors, particularly junior doctors, and to generate data which would honour their voices and experiences;

Conducting ethically robust research is important. For my primary data generation, detailed consideration of ethics is provided in Chapter 4.

2.6. Summary of research approach

Table 2. Summary of research approach

Aims	Research strategy		
1. To examine conceptions and understandings of the approach to the end-of-life among medical doctors	Scoping study and qualitative content analysis of medical literature (Chapter 3)	Semi-structured interviews with foundation doctors and inductive thematic analysis of data (Chapters 4 and 5)	
2. To explore experiences and understandings of doctors learning to care for patients at the approach to the end-of-life, including factors which provide barriers to learning			
3. To develop a theoretical explanation of the learning of doctors about the approach to the end-of-life among doctors			Generating a theoretical framework using Cultural Historical Activity Theory (Chapter 6)

2.7. Conclusion

This chapter has established and explained my critical realist perspective of science and socio-material view of education, and explained how these underpin this research. I have explained the aims of the research incorporated in constructing this thesis, and introduced my methodological approach to meet these research aims. I also discussed the use of my theoretical framework in this thesis, and discussed considerations related to research trustworthiness, encompassing research quality, reflexivity, and who I am as a researcher. In the following chapters, I will present the studies I have undertaken using the means discussed in these chapters, demonstrating how these research aims have been met. These will contribute to meeting the overall aim of this thesis: to develop an explanation of how medical doctors learn about and understand patients approaching the end-of-life.

3. Conceptions of the approach to the end-of-life among UK medical doctors – review and analysis of the medical literature

3.1. Introduction

This chapter presents a study addressing the research aim of examining how the approach to the end-of-life is conceptualised among doctors. It does this by exploring the conceptions raised in discussion of the approach to the end-of-life in the UK medical literature. The study incorporates a Scoping Study Methodology and Qualitative Content Analysis of the UK medical literature which discusses patients approaching the end-of-life.

Differences in understanding terms related to end-of-life care have been previously noted, and these discrepancies have potential repercussions for patient care, education and practice. The critical realist (CR) view of language is that whilst it is not a true reflection of the nature of reality, it is not arbitrary (Edwards, et al., 2014b). It is therefore important in this chapter to consider not only terms used, but what is meant by these terms.

Previous studies have explored definitions of individual or groups of pre-determined terms related to palliative medicine (Pastrana et al., 2008; Jünger et al., 2012; Bausewein and Higginson, 2012; Ewert, et al., 2016). This study differs as it does not pre-determine the terms of interest and aims to explore and map all terms and concepts. No previous studies have taken this inductive, comprehensive approach to exploring the breadth of terms related to patients approaching the end-of-life.

3.2. Methodology

In order to obtain a broad sample of language on which to carry out analysis, this study employed Scoping Study Methodology (SSM) and Qualitative Content Analysis (QCA) methodologies. While an SSM facilities descriptive analysis of finding, this study sought to go further, to analyse terms in order to explicate the concepts they represent. Combining SSM with qualitative analysis has been previously established (Martimianakis et al., 2015; Brydges et al., 2017). In doing so, I incorporated key guidance for literature searching (Haig and Dozier, 2003; Arksey and O'Malley, 2005) and advice from a health sciences librarian.

3.2.1. Research assistant

This study was designed and led by me, however I was assisted at some points in literature searching by a research assistant (Avril Dewar) and have clearly identified these elements in the text (AD). I conceived and designed this study, and carried out the analysis. I remain the main author of this work.

3.2.2. Scoping study

SSM exists to facilitate literature reviews which answer broad research questions and examine the scope of literature. This contrasts with systematic reviews which aim to answer a narrow research question, and potentially only include limited, homogenous

literature in their analysis. Arksey and O'Malley (2005) established the widely utilised framework for SSM. This study was carried out broadly according to the principles of this framework, and guidance from other authors (Levac, Colquhoun and O'Brien, 2010; Khalil et al., 2016). The framework consists of the stages described in Table 3.

Table 3. Stages of Scoping Study Methodology, adapted from Arksey and O'Malley (2005), Levac et al. (2010), Khalil et al. (2016)

Stage		**Description**
1	Identifying the research question	Establish a broad research question answerable through broad coverage of the literature.
2	Identifying relevant material to include	Identify relevant existing literature and devise a comprehensive search plan
3	Document selection	Post hoc development of inclusion and exclusion criteria, as the researcher becomes familiar with the material and its content.
4	Charting the data	A data-charting form is developed and used to extract data from each study.
5	Collating, summarising, and reporting results	Develop an overview of the breadth of the literature and present the nature of included materials.
6	Consultation	The opportunity for stakeholders and subject matter experts to suggest additional references and offer insights to the results of the findings. *(This stage is viewed as being optional)*

The methodology allowed for iterative refinement of the inclusion criteria and search strategy, which was appropriate as there is no universally accepted terms and the breadth of material under study could be known only after commencement. Although SSM may be done in advance of a further review, it is a research methodology in its own right (Arksey and O'Malley, 2005).

3.2.3. Qualitative Content Analysis

Traditional Content Analysis is quantitative, seeking to quantify certain terms in a data source, and make arguments based on this. In contrast, Qualitative Content Analysis (QCA) examines not only usage of terms, but also the context in which they are used and concepts that are represented (Elo and Kyngäs, 2008). I investigated the way the language is used in the documents – as a proxy for how doctors talk about these concepts. QCA examines both manifest (stated definitions) and latent meanings (implied by context) (Hsieh and Shannon, 2005).

3.2.4. Ethical considerations

No primary data generation was carried out in this study and there was no access to confidential material. Therefore there was no need for consideration by research ethics committee.

3.3. Methods

This study was carried out over three phases. Phases one and two constituted a scoping study to examine the scope of medical literature in which patients approaching end-of-life were discussed. The third phase employed QCA of identified literature, to examine terms used and concepts they represent. As analysis progressed, it generated descriptions of concepts discussed.

AD contributed towards Phases one and two, but not to Phase three. AD is a registered nurse who also has a degree in psychology. AD now works in medical education research and management of assessments at Edinburgh Medical School. Although not a medical doctor, AD's background allowed her to understand the research problem and to be an active and effective research assistant. Generating search criteria and identifying literature for inclusion with AD meant that the processes were not only agreed by a medical doctor (me) but also by a knowledgeable and insightful colleague who is not a medical doctor but has a good understanding of the issues under study.

3.3.1. Phase One – Construction of search strategy and inclusion criteria

I identified eleven key documents from my own practice as a doctor. I reviewed these and used terms they contained to develop a list of search terms. Further search terms were generated by discussion with AD about possible synonyms, until the search strategy was agreed (Table 4).

Table 4. Search terms used in literature search

Topic	AND	Subject
"Palliative care" OR "Supportive care" OR "End-of-life" OR "Sudden death" OR "Symptomatic relief" OR "Deteriorating patient" OR "Complex Symptom Burden" OR "Terminal case" OR "Incurable condition" OR "Progressive condition" OR "Illness trajectory" OR "Patient journey" OR "Patients Approaching End of Life" OR "Decline" OR "Imminent Dying" OR "Catastrophic Illness" OR "Advanced disease" OR "Anticipatory Care" OR "Ceiling of Care" OR "DNACPR" OR "End stage" OR "Life threatening" OR "Limited reversibility" OR "End of life" OR "Unstable" OR "End-journey"		"Physician" OR "Consultant" OR "Fellow" OR "Resident" OR "Medical graduate" OR "Foundation doctor" OR "GP" OR "Doctor in training" OR "Trainee" OR "Intern" OR "Specialist" OR "Healthcare Professional" OR "Medical Student" OR "MDT" OR "Medical professional" OR "Hospital staff" OR "Doctor" OR "Junior Doctor" OR "Medic" OR "General practitioner" OR "Multidisciplinary Team" OR "Multi-disciplinary Team"

A systematic search of Web of Science, PubMed, and EbscoHOST was carried out in September 2016 resulting in 3174 items. In order to cover a range of data sources (Haig and Dozier, 2003), a hand search of non-database websites was performed (National Institute for Health and Care Excellence, 1997; Cochrane Library, 2000; Health Improvement Scotland, 2010; Scottish Palliative Care Guidelines, 2015a), resulting in 113 further results. Nine documents were retrieved by ancestry searching[2] of the original eleven documents. The results of the systematic search, ancestry search and the hand search were combined to give a result of 3296. References were collated on *EndNote* (Clarivate Analytics, 2016).

Fifty papers were initially reviewed (by AD and myself) to begin exploration and develop inclusion criteria. Included publications were those written in English language for clinical education, guidance or professional development of medical doctors. Documents of any type were included: research using any method; case studies; essays; letters; non-defunct guidelines. This study focused on contemporary use of language, and so only publications from the previous 10 years (2006-2016) were included. Documents were included if they discussed patient care in the UK, regardless of geographical location of authors, and regardless of cause of death discussed.

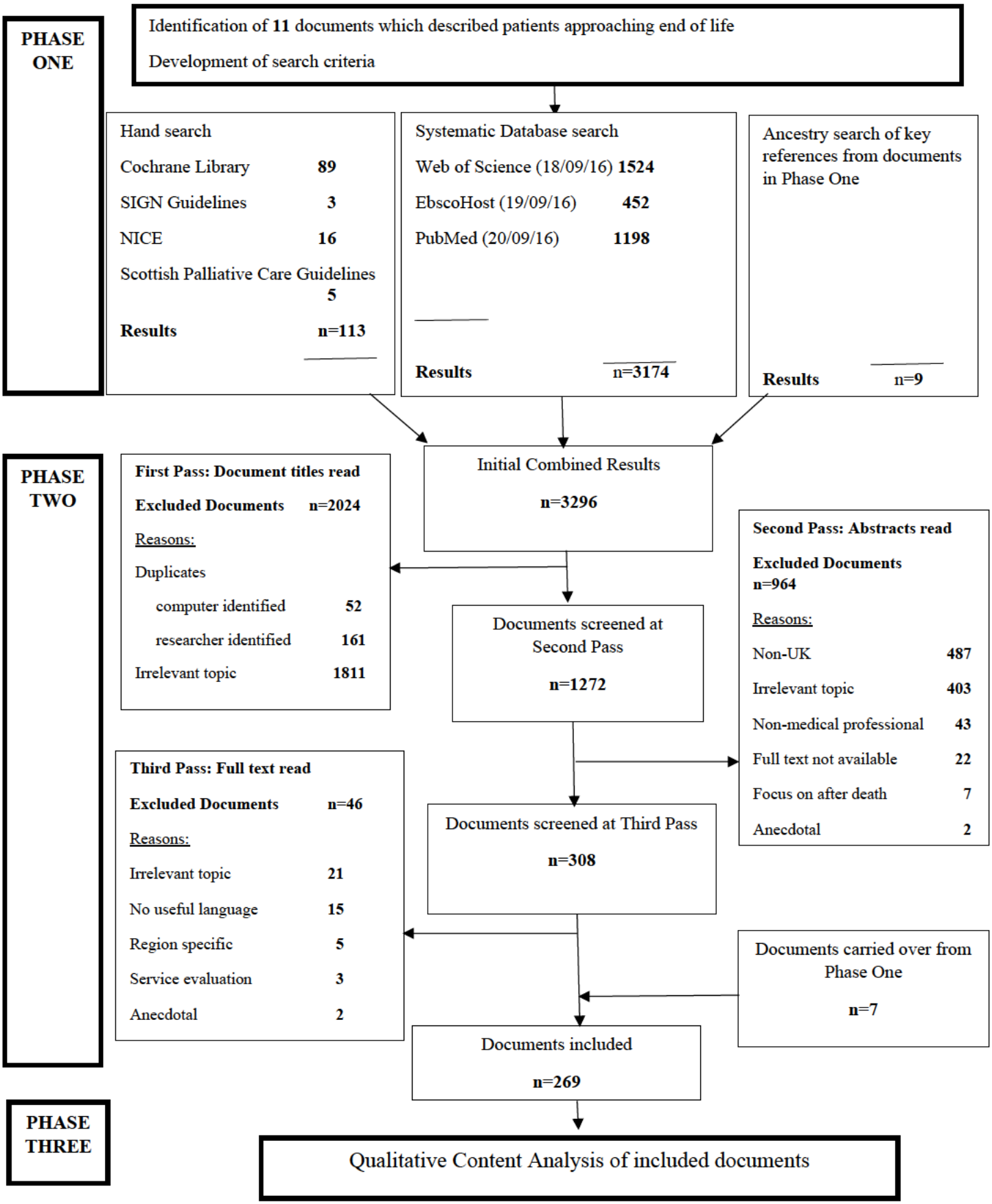
Publications were excluded if they discussed veterinary medicine; were written for non-medical healthcare professionals or discussed deaths in nursing homes; were guidelines relevant only to one clinical site or were economic evaluations. Articles which discussed processes after death, were non-written materials, anecdotal, non-clinical reflections or art were also excluded.

[2] Ancestry searching is the process of identifying literature for inclusion by reviewing the reference lists of literature which has already been identified (Poirier and Behnen, 2014).

3.3.2. Phase Two – Document selection and data extraction

Fifty-two duplicates were removed using *EndNote*, and a further 161 duplicates were identified by AD and myself and removed. The remaining papers were reviewed individually (by AD and myself) and excluded according to the criteria established in Phase One. An initial pass was carried out by reading only article titles and 1811 documents were excluded. During a second pass, abstracts from the remaining 1272 documents were reviewed and 964 documents excluded. During a third pass the full texts of the remaining 308 documents were read and forty-six documents excluded. Seven of the documents which had been used to generate search terms in Phase One were included in the final numbers also. Figure 6 shows the selection process and reasons for exclusion.

Figure 6. Scoping study selection process including reasons for exclusion



At each pass, if there remained uncertainty, documents were included to next pass until more information was available or it was established that the full text was unobtainable. I designed an extraction template using *Excel* (Microsoft, 2016) and refined throughout the selection process our familiarity with the material increased. The documents which were included in analysis are listed in Appendix 6.

3.3.3. Phase Three – Qualitative content analysis of key concepts

Analysis was recorded using the software package *NVivo* (QSR International, 2015). I sought for analysis to be based on language in the documents and developed inductively, therefore I did not use a pre-established framework. I noted similar concepts appeared repeatedly and I coded these using *in vivo* terms generated from the text (Saldana, 2015). Analysis and interpretation of these concepts led to description of their meanings as represented in the texts, and contexts in which they are used.

3.4. Results

3.4.1. Document characteristics

Two hundred and sixty-nine documents were included, comprising: one hundred and eighty-two research studies; three protocols; thirty-one guidelines; seventeen review papers; seven opinion pieces; six editorials; five letters; three case studies; three white papers; two transcripts from symposia; two policy documents; two consultation reports; two news articles; one clinical audit; one quality improvement project; one questionnaire; one book chapter (see Table 5).

Table 5 – Characteristics of included documents

Document characteristic		No.
Year of Publication	2006	13
	2007	11
	2008	19
	2009	23
	2010	22
	2011	27
	2012	28
	2013	40
	2014	28
	2015	38
	2016	20
Document Type	Research Study	182
	(Abstracts)	(3)
	(Journal articles)	(178)
	(Research letters)	(1)
	Research study protocol	3
	Clinical guideline	31
	Review	17
	Commentary or opinion	7
	Editorial	6
	Letters to the Editor	5
	Case Study	3
	Government white paper	3
	Reports of consultations or consensus agreements	2
	News article	2
	Transcripts from lectures or symposia	2
	Policy or position document	2
	Quality Improvement Project report	1
	Clinical audit report	1
	Clinical questionnaire	1
	Book Chapter	1
Research Type (n=182)	Qualitative study	77
	Cross-sectional questionnaire	30
	Retrospective analysis of case notes	18
	Other observational study	9
	Systematic review	17
	Other review type	14
	Mixed methods study	7
	Randomised Controlled Trial	5
	Other experimental study	2
	Modified Delphi study	2
	Other	1

Publishing Institution (determined by address of corresponding author)	University	154
	Hospital/secondary care department	73
	Hospice/specialist palliative care department	17
	Community health centre/primary care department	5
	Medical Royal Colleges	4
	NHS Scotland	4
	National Institute for Health and Clinical Excellence	3
	Medical professional society or association	2
	UK Government Department of Health	1
	Scottish Government	1
	General Medical Council	1
	Cochrane Library	1
	Scottish Intercollegiate Guidelines Network	1
	National Clinical Guidelines Centre	1
	UK Resuscitation Council	1
Disease or body system discussed	Cancer (including haematological and other body systems)	39
	Respiratory non-cancer conditions (including cystic fibrosis)	16
	Renal non-cancer conditions	6
	Cardiac non-cancer conditions	18
	Dementia	12
	Other neurological non-cancer conditions	10
	Frailty	2
	Intellectual disability	3
	Diabetes Mellitus	2
	Rheumatological non-cancer conditions	1
	Burns	1
	Stroke	1
	Non-specific	158
Age group of patients discussed	Specified as adults	4
	Specified as children and young people	14
	Specified as older adults	11
	Not specified	240
Geographical location of first author	England	214
	Scotland	23
	Northern Ireland	8
	Wales	6
	Spain	6
	Netherlands	3
	Italy	2
	Sweden	2
	Australia	1
	Cyprus	1
	Denmark	1
	Israel	1
	Germany	1

3.4.2. Results of Analysis

As the study progressed, analysis led to development of concept headings. In presenting the results, references are provided as representative examples of data sources. Overall results presented in Table 6.

Table 6. Results of Qualitative Content Analysis of included documents.

Over-arching category	**Constituent categories**	**Emerging concepts**
The patient and their illness	Type of condition	Progressive illness Advanced condition Life limiting conditions
	Deteriorations	Reversible and irreversible deteriorations Unpreventable dying Sudden deteriorations Risk of deteriorating and dying
	Predicting death and deteriorations	Recognising dying Prognostication Death becomes increasingly probable
	Living with illness	Journey or transition Disease trajectory Supportive and palliative care needs
The care of the Patient	Default medical care	Curative potential Active treatments Escalating medical care Cardio-pulmonary resuscitation
	Negative conceptions of care	Inappropriate Overtreatment Futile Aggressive
	Planning in advance	Advance care planning Preferred place of care Do not attempt cardio-pulmonary resuscitation
	Positive conceptions of care	Palliative care Supportive care Conservative care End-of-life care Care of the dying Withholding and withdrawing treatments

3.4.2.1. The patient and their illness

The thirteen concepts within 'The patient and their illness' have been further categorised according to the elements of approach to end-of-life they consider: types of conditions; deteriorations; predicting death and deteriorations; living with disease.

3.4.2.1.1. Types of condition

The patient's approach to end-of-life was often considered in terms of their condition. This may be *progressive illness*, describing a chronic illness progressing over time until reaching a stage at which death is inevitable. Progression from diagnosis may be variable and lead to reduced quality of life, e.g. dementia eventually progresses to death, unless the patient dies from inter-current illness (Birch and Draper, 2008). A*dvanced condition* was also used, typically to describe later disease stages, at which prognosis is more certain (Gardiner et al., 2010; Gadoud and Johnson, 2011; BMA, 2016a), although not synonymous with dying itself (Bajwah et al., 2013). Idiopathic Pulmonary Fibrosis is considered as an advanced condition when there is no further opportunity for treatment options and lung transplantation is unsuitable (Bajwah et al., 2015).

The concept of *life limiting conditions (LLCs)* emerged where the focus is shortened life expectancy. This was most often in documents discussing children, with the expectation of not reaching adulthood. Beecham et al (2015) described LLCs as "any condition from which there is no reasonable hope of cure and from which the child or

young adult will die prematurely" (p. 3). However, others (Boland et al., 2013; Hain et al., 2013) highlighted that LLCs encompass conditions with potential for cure.

3.4.2.1.2. Deteriorations

As patients near the end of their life, episodes of worsening physical condition were described as *deteriorations*. These deteriorations may lead to death or have potential for reversal. Stated *reversible* causes of deterioration included dehydration, infection, opioid toxicity, steroid withdrawal, delirium, hypercalcaemia, hypoglycaemia (Scottish Palliative Care Guidelines, 2015b; Cocks et al., 2016). The very end-of-life may be described in terms of there being no (or limited) potential for *reversibility*, and that cases with no reversibility should be identified promptly as *unpreventable dying* (Bennett, Brodrick and Stirling, 2015). This suggests that patients should be considered as dying only when they have suffered a deterioration with no reversible cause or attempts at reversal are unsuccessful. In contrast, others (Cocks et al., 2016) argued that reversible causes of deterioration should not necessarily be acted upon; attempting to reverse deteriorations is not always in the patient's interests. This indicates a conception of the approach to the end-of-life in terms of deterioration but more broadly than whether reversible.

There may be indicators in the patient's condition of general deterioration. Doctors should be conscious of the risk of these *sudden deteriorations* that may lead to death in patients with chronic disease (Barnes and Campbell, 2010). Some documents (Blackwood et al., 2015; University of Edinburgh, 2016) indicated it is those *at risk of deterioration or dying* for whom care priorities should be re-evaluated. Patients may

therefore be considered as approaching end-of-life even if they are at *risk* of deterioration which may lead to death.

3.4.2.1.3. Predicting death and deteriorations

Various descriptions emerged of *recognising dying*. However, I identified discrepancies regarding what should constitute this, e.g. those likely to die within the next 12 months (Royal College of General Practitioners, 2011); those whose death within 12 months would not be surprising (Department of Health, 2010); patients in the last few months of life (Royal College of General Practitioners, 2015); patients in the last few days or hours or life (Brooks, 2014); patients for whom recovery is uncertain (Barnato et al., 2011; Carey, Smith and Shouls, 2015).

Prognostication is a further concept related to predicting dying and encompasses when a patient may be expected to die, likely responses to treatments, and when patients may be expected to deteriorate (Boland et al., 2013). The importance of doctors prognosticating accurately and timeously is described, to facilitate preparation for death. Prognostication may be more straightforward in cases of malignant disease, but remains difficult regardless (Al-Qurainy, Collis and Feuer, 2009).

Predicting patient death is also described in terms of the probability of death. This reflects a stage when *death becomes increasingly probable*. Potential triggers for considering this include new diagnoses of life limiting illnesses; deteriorations; multiple hospital admissions (Barclay and Maher, 2010).

3.4.2.1.4. Living with illness

Living with a disease leading to death has been described as being like a *journey or transition* (Coombs, et al., 2012). This describes events which occur for the patient living with disease as it progresses over time until there is an eventual transition to an end stage, i.e. 'terminal', represents a phase of disease rather disease itself (Seymour et al., 2010). The patient's journey is affected by medical interventions and advances, e.g. may be postponed for patients with renal failure by renal replacement therapy (Taylor et al., 2016).

Disease trajectory is a further concept which describes the course of a patient's life with a condition which will lead to death, including rate of decline and deteriorations (Murray and Yang Kok, 2008). Trajectories differ and are influenced by available treatments. Typical trajectories have been defined: cancer; organ failure; frailty. Generally, the trajectory for non-malignant conditions are more difficult to define and predict. Continuing certain treatments to the end-stage of the trajectory is detrimental (Brighton and Bristowe, 2016). No trajectories related to patient recovery were described.

The concept of *supportive and palliative care needs* refers to needs of the patient, differs from the concepts above which describe the approach to end-of-life in terms of length of life or disease stage. Ream et al (2008, cited in Maguire et al., 2015 p.449) defined supportive care needs as "requirements for patient care pertinent to the management of symptoms and side effects, enablement of adaptation and coping, optimisation of understanding and informed decision-making and minimisation of functional deficits". Although the terms supportive care and palliative care were described together, they are referred to as separate concepts, but I was

unable to identify from the data how they differ. Discussion of palliative care needs suggests identifying them in patients may be a more fruitful aim than identifying dying (University of Edinburgh, 2016).

3.4.2.2. The care of the patient

Analysis indicates that the approach to the end-of-life was also conceptualised according to healthcare administered to or available to the patient by doctors. Interpretation of the seventeen concepts within 'the care of the patient' category is presented here. These concepts have been further categorised: default medical care; negative conceptions of care; planning in advance; positive conceptions of care.

3.4.2.2.1. Default medical care

The role of the doctor is often perceived as to provide treatments with *curative potential*. This may lead to patients assuming treatments they receive have the aim of curing them, even if it is to provide symptomatic relief (Barclay, 2010). The distinction between what is a curative treatment and supportive care is not always clear, e.g. chemotherapy (Grunfeld et al., 2006). Treatments with and without curative potential may be given alongside one another (Harding, 2013).

Active treatments describe those given with the aim of prolonging life (Howell et al., 2015) including clinical investigations, and surgical and medical interventions (Fritz et al., 2014b). Active treatment of patients is discussed in contrast with treatments which aim to give symptomatic relief (Coombs, et al., 2012a; Howell et al., 2015).

However, others indicate patients may receive active treatments concurrently with symptomatic treatments (Puckey and Bush, 2011). Furthermore, patients who have not been receiving treatment with life-prolonging intent, may yet receive active treatments if their clinical situation changes, e.g. a patient in a hospice may be referred for active treatment of spinal cord compression (Tunnicliffe and MacKay, 2011).

When a patient's condition becomes increasingly unstable, clinical actions are made to increase the intensiveness of attempts to prolong the patient's life. The ongoing increase in intensiveness of patient care is referred to as *escalating medical care*. For example, a patient at home may require hospitalisation for life-prolonging treatments (St Ledger et al., 2013; Blackwood et al., 2015). For patients already admitted to hospital, this may include referral to critical care for more intensive treatment (Beckett et al., 2013). The increase in intensity of treatment will occur until/unless there are specific decisions to limit this. This indicates the default presumption in favour of escalating medical treatment unless otherwise stated.

One frequently discussed example of a life-prolonging intervention, and aspect of escalating medical care, is *cardio-pulmonary resuscitation*. Doctors often can, and should, identify patients at risk of suffering a cardiac arrest (Brims, Kilminster and Thomas, 2009; Tyrer et al., 2009). The default presumption is that CPR will be performed on patients who experience cardiorespiratory arrest (Holland, Bowker and Myint, 2013; Cocks et al., 2016). Those who are receiving active treatment would receive CPR unless decided against specifically (Fritz et al., 2014). This suggests a difference between cardiopulmonary arrest – the cessation of the patient's heart and lungs functioning spontaneously – and death, depending on the circumstances and acceptance that the patient is dying.

3.4.2.2.2. Negative conceptions of care

Care received by patients approaching the end-of-life was often discussed negatively when patients received aspects of normal default medical care which are considered *inappropriate* (Lawrence et al., 2011; Sheard et al., 2012). Failure to alter the treatment plan accordingly for a patient approaching the end-of-life is inappropriate. Continuing inappropriate treatments may result in patients receiving *overtreatment* (Ryan et al., 2012). It is often not possible to determine overtreatment until considering events retrospectively (Dehnel, 2014).

For patients who are approaching the end-of-life, continuing or administering certain treatments were considered *futile* (Danbury and Waldmann, 2006). Various definitions of futility exist, e.g. Schneidermann (2011, cited in Price and Haxby, 2013) described futility as the "unacceptable likelihood of achieving an effect that the patient has the capacity to appreciate as a benefit." It is the responsibility of doctors to identify futility in order to prevent an undignified and distressing death (Danbury and Waldmann, 2006).

Treatments for patients approaching the end-of-life were also sometimes conceptualised as *aggressive* (Lowton, 2009), e.g. attempts at CPR and invasive ventilation intubation (Nava et al., 2007). Aggressive treatments represented a failure to acknowledge the patient was approaching the end-of-life, failure to provide a good quality of care, and reducing the quality of the patient's remaining life (Lawrence et al., 2011).

3.4.2.2.3. Planning in advance

A*dvance care planning* (ACP) is a means to reduce likelihood of patients receiving poor care towards the end-of-life, and facilitate them having a better quality of life (Barnes et al., 2012; Lund, Richardson and May, 2015). Definitions and understanding of ACP vary, e.g. a process (Horridge, 2015); a conversation (Blackwood et al., 2015); a means to overcome communication difficulties (Kite, 2010); a legal framework (Al-Qurainy, Collis and Feuer, 2009); an ethical framework (Lund, Richardson and May, 2015). Components of ACP may include Advanced Decisions to Refuse Treatment, Do Not Attempt CPR (DNACPR) decisions, Power of Attorney (Joseph, Chapman and Regnard, 2010), artificial feeding, ventilator support (Barnes and Campbell, 2010). Generally, it is desirable for ACP to be discussed before they are very close to the end-of-life, although this is not always possible (Blackwood et al., 2015).

An important aspect of ACP is discussion of the *patient's preferred place of care (PPOC)* (Evans et al., 2014; Mitchell and Dale, 2015). In the absence of ACP, dying patients would be admitted to hospital. This corresponds to the concepts of 'escalating medical care' (above). Often, the patient's own home is perceived as the most desirable place for dying patients (Lowton, 2009).

Decisions around CPR are another aspect of ACP. As described above, CPR is conceptualised as aggressive and futile when administered to patients approaching the end-of-life. If CPR is performed, it frequently does not prolong life (Miller and Dorman, 2014). Even if cardiac output returns following CPR, there are frequent patient complications after cessation of cardiorespiratory arrest, and low numbers of patients survive to discharge from hospital (Tyrer et al., 2009). Cocks et al (2016)

described factors in favour of patients receiving CPR – therefore those not associated with the approach to the end-of-life – including acute reversible illnesses, treatable arrhythmias, otherwise healthy people admitted with a relatively minor illness, out-of-hospital arrests in public. However, incidences of CPR leading to a patient returning to full health are few (Scott, 2010; Campbell et al., 2011).

Do not attempt cardiopulmonary resuscitation (DNACPR) decisions declare that CPR should not be performed. The aim is prevention of unwanted and inappropriate CPR, and the decision should be documented (Low et al., 2014). After such a decision exists, it would be poor practice for CPR to be carried out for that patient (Beckett et al., 2013). DNACPR decisions may be made by the medical team caring for the patient (Cocks et al., 2016), influenced by, for example, patient's diagnosis, prognosis, age, quality of life, the opinions of doctors and other medical staff, and the wishes of patients and relevant others (Tyrer et al., 2009).

3.4.2.2.4. Positive conceptions of care

Palliative care is often discussed in contexts focusing on patients approaching the end-of-life. Two separate concepts emerged from analysis: generalist palliative care –delivered to the patient, as is provided by all levels of health service and all health professionals across disciplines (Dale et al., 2009; Kite, 2010; Cocks et al., 2016) – and specialist palliative care – denoting a medical specialty, the care provided by an experienced expert or the name of a specialist unit (Higginson and Evans, 2010). It is incorrect to conflate generalist palliative care with specialist palliative care (Turner-Stokes, Sykes and Silber, 2008). Here, generalist palliative care is explored, i.e. the *care* itself provided to the patient by health professionals.

Palliative care is separate from care of patients at the very end-of-life. For example, in some texts it was described separately from end-of-life care (The Scottish Government, 2008; Andersen et al., 2007). Others stated that although palliative care should facilitate end-of-life decision making and advance care planning (Turner-Stokes, Sykes and Silber, 2008), palliative care is wider than this (Gibbins et al., 2009; Barclay et al., 2015). Palliative care should be provided early in an illness, not only at the stage of dying (Kydd and Sharp, 2016).

There is no standard meaning of palliative care that is consistently adhered to (Birch and Draper, 2008; Gibbins, et al., 2009; Bausewein and Higginson, 2012). Palliative care was generally described as an approach to increasing quality of life of patients (Andersen et al., 2012; Charalambous et al., 2014) and their families (Kernohan et al., 2006). The World Health Organisation definition of palliative care is frequently cited (e.g. Bajwah et al., 2012 p. 215): ‘‘an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual’’. In contrast, chemotherapy which is provided to extend length of life of a patient was stated as an example of palliative care, as it does not lead to cure, even though it is different from symptom control for improved quality of life (Howell et al., 2011). Howell (2015) described palliative care as part of a transition from active treatments. Others report that palliative care is compatible with active treatments (Puckey and Bush, 2011). Gibbins et al. (2009) argue that it is a misconception that patient receiving palliative care should always receive care only at normal ward level, presenting a clinical example of such a patient who was appropriately admitted to the intensive care unit.

Conflicting understandings of palliative care may cause confusion among the public (Kydd and Sharp, 2016) and health professionals (Ingleton et al., 2013). Despite discrepancies, there is much agreement of its importance. Palliative care is mentioned as being required by patients with life-limiting conditions (Hain et al., 2013) and that as the world's population ages, more people will require palliative care (Davies et al., 2014). Palliative care should be considered for certain patients from the time of diagnosis (Andersen et al., 2007), those with chronic health conditions (Arris, Fitzsimmons and Mawson, 2015), those with distressing symptoms, when there is need to consider end-of-life planning (Arolker et al., 2010), and those with complex needs (Burt and Raine, 2006).

Supportive care was a further concept lacking universal or consistent meaning and the distinction between supportive care and palliative care is unclear. At times it was mentioned separately from palliative care (Ewing, Farquhar and Booth, 2009; Cocks et al., 2016), at others it was stated that supportive care was another name for palliative care (Bausewein and Higginson, 2012). The provision of supportive care may be a part of palliative care (Howell et al., 2011), but elsewhere supportive care is described as encompassing palliative care (Cawley et al., 2011), and that palliative care increases the possibility of supportive care being provided (Selman et al., 2009). Supportive care may be care where disease-modifying treatment is no longer being provided (Barclay, 2010), care which is patient-centred and identifies and responds to the patient's needs (Maguire et al., 2013), and care where the patient's comfort should be the priority (Fritz et al., 2014). Examples provided of supportive care included analgesia, minimally invasive treatments including paracentesis (Fritz et al., 2014), and radiotherapy for pain control in patients with cancer (Cocks et al., 2016).

Conservative care was an option for patients which involved a decision not to proceed with invasive treatments of a disease and was contrasted with active treatments (discussed above). Conservative care arose in literature discussing patients with end stage renal failure deciding not to undergo haemodialysis when there is limited expected benefit (van der Luijtgaarden et al., 2013). Conservative care was also conflated with both supportive and palliative care (Johnston and Noble, 2012).

End-of-life care (EOLC) arose as a separate concept from palliative or supportive or conservative care. However, meanings ascribed to EOLC differed vastly. Papavisilou et al., (2013) related EOLC to care of dying patients in the last few hours or days of life, and Frank (2009) related it to impending death. In contrast, the BMA (2016a) defined EOLC at the total care of patients with "advanced incurable illness", and stated that it may last for days, weeks or longer. EOLC was otherwise referred to in reference to care for patients in their last year of life (Shipman et al., 2008), care for those at risk of dying from a sudden acute crisis in a chronic condition (Wee and Barclay, 2012), and care for patients with incurable conditions and their families (NICE, 2011). However, the importance of good quality EOLC was a consistent theme, and it was seen as a priority for health services (Ambrosino and Simonds, 2007) and doctors (Arolker et al., 2010), and should be provided regardless of the condition affecting the patient (Lawrence et al., 2011; Bakhai, O'Sullivan and Riley, 2013). Good quality EOLC included holistic assessment (Wee and Barclay, 2012); open communication with patients (Barclay et al., 2011; Brighton and Bristowe, 2016); prevention and relief of physical, psychological and spiritual suffering (BMA, 2016a); support for maintaining autonomy; use of advanced care planning; satisfaction of patient and family; education for patient and family (Gardiner et al., 2010); choice over place of death (Frank, 2009; Hunt, Shlomo and Addington-Hall,

2014); and stopping non-essential drugs (Sleeman and Collis, 2013; van der Cammen et al., 2014).

Care of the dying concerns care of patients imminently before their death. Care of the dying was considered as an aspect of palliative care (Cocks et al., 2016), and was the responsibility of every doctor at all career stages, even the most junior ones (Gadoud et al., 2012; Price and Schofield, 2015). The patient's home as a place of death was frequently seen as the best option from the point of view of patient (Lowton, 2009), and deaths occurring at home were one measure of quality of care of the dying (Department of Health, 2010). However, excellent care of the dying is a vital part of the work of acute hospitals (Yang, Ewing and Booth, 2012), but this was not always achieved. For example, Hanratty (2006) reported care of the dying was frequently poor, and Cohen (2008) indicated deaths in hospital could be viewed as poor care. In contrast, Brooks (2014) suggested the majority of hospital care of the dying was good quality, citing, from 'The National Care of the Dying Audit for Hospitals', that 68% bereaved carers were likely or extremely likely to recommend the hospital trust which had cared for their dying loved one.

Better care of the dying was that which facilitates: fewer unwanted treatments; fewer hospital admissions; less anxiety and depression (Steel and Goldring, 2015); death in the patient's preferred place (including rapid transfer to the patient's preferred place); discussion of prognosis; decisions about CPR (Scottish Palliative Care Guidelines, 2015b, 2015c; Arnold, Finucane and Oxenham, 2015); sensitive and good quality communication (Gillett, O'Neill and Bloomfield, 2016); individual, patient-centred care (Janssen and MacLeod, 2010); absence of pain or other symptoms (Bennett et al., 2015); patient autonomy (Borgstrom, Barclay and Cohn, 2013); food and drink; psychological and spiritual support (Brooks, 2014a); access to information

and expertise; patient control over who is present at the moment of death; and not having life prolonged pointlessly (Hicks, 2012). Good quality care of the dying could be achieved through comprehensive ACP (Steel and Goldring, 2015). Ongoing medical interventions (Burki, 2013; Blackwood et al., 2015) and hospital admissions (Young et al., 2013) could lead to poorer quality care of the dying.

Withdrawing and withholding treatments are commonly discussed concurrently as good practice frequently discussed in connection with the concept of futility (described above) (Finlay, 2006; Clarke et al., 2015). Treatments discussed include ventilation (LeBon and Fisher, 2011; Gupta et al., 2013), de-activation of implantable cardiac defibrillators (Hill et al., 2015), haemodialysis (Hussain et al., 2015), and cessation of drugs including chemotherapy (Williams et al., 2007; Owen and Jeffrey, 2008). Decisions about withdrawing and withholding treatments are challenging, particularly in areas where new treatments are being developed (Nava et al., 2007; Goggin, 2012). There may be no clear guidance on how and when to withdraw certain interventions (Faull, Rowe Haynes and Oliver, 2014) and this must be considered judiciously: the unnecessary withholding of hydration for dying patients may be poor care of the dying (NICE, 2015).

3.5. Discussion

3.5.1. Consolidating results

This scoping study and QCA has examined how UK medical doctors understand the patient's approach to the end-of-life, and which concepts influence this understanding. This analysis was undertaken inductively, unlike previous studies which have studied one or a group of pre-determined terms (e.g. Bausewein and Higginson, 2012; Papavasiliou et al., 2013). This is the first study to examine the broad scope of concepts referred to in discussions of patients approaching end-of-life in medical literature. This study is also novel in its focus on generating insights for workplace learning. As I will explain, this scoping study and analysis has led to two main achievements in addressing its aim.

Firstly, it has demonstrated a variety of ways in which the approach to end-of-life is conceptualised in literature with the intended audience of UK medical doctors. We can see from the findings that the approach to end-of-life is conceptualised in ways connected to the doctor's practice: the assessments made by doctors of the patient and their disease; medical care available and perceptions of the care.

Secondly, the findings have demonstrated inconsistencies in meanings and in what is significant when conceptualising the approach to the end-of-life. These outcomes will be discussed in detail below. I will then discuss the contribution of this study to advancing this thesis, potential wider implications, and strengths and limitations of this study.

3.5.1.1. Conceptualising the approach to the end-of-life

Concepts emerged from this inductive analysis, and I have delineated how these varied in how they relate to the approach to end-of-life. From this analysis, I argue that the approach to the end-of-life is not considered as a discrete entity, but in relation to its wider meanings and effects. These include meanings ascribed to the patient and the actions of the medical team. This is parallel to the notion of the social construction of illness, which is a widely utilised framework in medical sociology (Conrad and Barker, 2010). In the social constructionism tradition, meanings of phenomena are considered as made through social interaction, and the importance of cultural and historical influences are highlighted (Berger and Luckmann, 1966). The social construction of illness incorporates not only a material, biomedical, invariable view of the patient's condition – the 'disease' – but also considers socially and culturally mediated aspects of the condition: the 'illness' (Timmermans and Haas, 2008). From this perspective, illness is not considered only based on biological essentialism, but cultural meanings ascribed to the illness, the experience of patients, and the construction of medical knowledge are also considered. Death and dying may also be considered as socially constructed (Conrad and Barker, 2010). Although there is a clear material biomedical component, understanding death and dying incorporates more factors including social organisation, cultural norms, beliefs and values (Van Brussel and Carpentier, 2014).

Similarly, this study has described conceptions of the approach to the end-of-life in relation to social and cultural factors. I separated conceptions into two over-arching categories depending on which aspects they considered: 'the patient and illness' and 'the care of the patient'. Thirteen conceptions were categorised as related to the

'patient and their illness'. In this category, differing concepts exist about how the patient and their illness influence understanding of the approach to the end-of-life. These included conceptions related to types of condition affecting the patient, whether the patient is deteriorating, and living with illness. These do not conceive the approach to the end-of-life as static, and do not rely purely on biomedical factors. Instead, these can be seen to incorporate dynamic social and historical considerations such as the effects of changes over time (*progressive illness, transition from diagnosis to terminal end stage*), potential to change over time (*prognostication, risk of deteriorating and dying*), changing needs of the patient (*supportive and palliative care needs*), responses of patient and/or illness to treatment (*advanced condition*), and availability of treatments (*trajectory*). Judgements by the doctor are incorporated in conceptualising the approach to the end-of-life including of the patient's best interest, and judgements about the likelihood of recovery.

Seventeen further conceptions are categorised as referring to the 'care of the patient'. Within this category, the approach to the end-of-life was expressed with reference to care available and/or the actions of doctors and other healthcare professionals. Certain concepts within this category were considered to relate to harmful, damaging or otherwise negative care, while others were discussed in positive terms. This led to an understanding that regular default medical care was that which was not designed for patients approaching the end-of-life and which was with curative or life-prolonging intent (*curative potential, active treatments*). For the patient approaching the end-of-life, the normal care provided by doctors is conceived negatively (*inappropriate*, *aggressive*). Through a process of planning in advance (*advance care planning, DNACPR*), patients approaching the end-of-life may receive care

which is conceived more positively (*palliative care, care of the dying, withholding and withdrawing treatments*).

Despite ambiguities within and overlap between the concepts, common messages may be interpreted across concepts. There is strong agreement of the vital importance of providing good quality care of patients approaching the end-of-life. The positive concepts of care were those incorporating reduction of distressing symptoms, being patient-centred and holistic. It was also regarded as important for care to be minimally invasive or avoiding invasive treatments, stopping or not offering certain treatments, reduction in hospital admissions and facilitating deaths outwith the hospital setting. This contrasts with concepts of default medical care whereby the hospital care is orientated towards extending life and giving increasingly invasive care to further this goal. For the patient approaching the end-of-life, the fewer the medical interventions, hospital care and hospital contact, the better the care for the patient approaching the end-of-life.

3.5.1.2. Inconsistencies in conceptions

Despite the agreement of its importance, there is lack of agreement of what constitutes the approach to the end-of-life. This corresponds with previous commentators who have noted lack of uniformity in definitions related to palliative care (Pastrana et al., 2008; O'Connor et al., 2010; Bausewein and Higginson, 2012; Maciasz et al., 2013; Ewert, et al., 2016). This study highlights the variety of ways of conceptualising palliative care and difficulty ascertaining when palliative care begins. Furthermore, there was some overlap and similarities between categories, e.g. the ambiguity of difference between palliative care needs and supportive care needs

('The patient and illness' category) can be seen in the confusion over the distinction between palliative care and supportive care ('The care of the patient' category). Although the lack of a unifying definition of palliative care is previously established, this alone is not presented as a principle new finding in this chapter. This study has gone further to demonstrate differing conceptions of the approach to the end-of-life which go beyond palliative care.

For example, the approach to the end-of-life may be considered in terms of different ranges of the patient's remaining life, those whose recovery is uncertain, those whose death would not be surprising. These are similar but not equivalent conceptions. In another example, the conceptual barriers between positive conceptions were inconsistent and overlapping, e.g. where *end-of-life care* began, how *supportive care* corresponds with *active treatments* or other concepts within the *default medical care* category.

It is not only language which is inconsistent, but more importantly the conceptualisations represented. The inconsistencies in conceptions therefore indicate that there is no clear single means of understanding the approach to the end-of-life. This suggests that the approach to the end-of-life is understood in ways which are subjective, context-dependent and malleable.

3.5.1.3. Advancing the thesis

This study aimed to explore how the approach to the end-of-life is conceptualised by medical doctors. Based on the findings, I have argued that understandings of the approach to end-of-life among medical doctors are subjectively and inconsistently

constructed in ways linked to their practice. The approach to the end-of-life is not understood uniformly as a discrete, disembodied concept, but married to social, cultural and organisational factors.

Furthermore, the findings indicate the cultural context and challenges faced by medical professionals: it is important to be able to understand someone is dying in advance, but there is no agreement on what constitutes this understanding. It is important not to continue inappropriate treatments, but it is difficult to know if you are over-treating a patient without the benefit of hindsight. Moreover, medical doctors operate within a system which is designed to provide care which prolongs by default, which is negative. Therefore, following this study difficulties faced by medical doctors when providing care for patients approaching the end of life can be better understood.

The findings align with the socio-material view of learning of this thesis. That is to say, the individual does not learn and understand in advance or separate from practice. On the contrary, individuals learn, and are influenced by the human and non-human factors with which they interact in their practice (Fenwick, 2010a).

This thesis aims to develop an explanation of how medical doctors learn about and understand patients approaching the end-of-life. This chapter has explored how the approach to end-of-life is understood by UK medical doctors, and emphasised that learning is connected to the work and workplace. In advancing this thesis, I argue that it is necessary next to consider the learning of medical doctors in the workplace, including the organisational and systems-based factors which influence this learning. In order to achieve this aim, the next study presented will examine experiences of UK medical doctors in the hospital setting.

3.5.2. Wider significance of study

In addition to its achievement in advancing my thesis, the study described in this chapter has wider relevance to medical education and healthcare. Differing understandings of significant concepts can lead to patients not receiving appropriate care. This phenomenon may include misperceptions that 'palliative' denotes only patients for whom life-saving treatments should never be given (Gibbins, Smith and Forbes, 2008), or, conversely, negative connotations may delay appropriate referral to 'palliative services' (Maciasz et al., 2013). Language also influences patients' perspectives and choices (Nickel et al., 2017) and the lack of a *lingua franca* between health professionals and patients may empower staff preferentially over patients (O'Connor, Davis and Abernethy, 2010). Based on the present study, it would be prudent for clinicians and policy makers to be careful with language, and not assume understandings are shared. This is particularly concerning for care of patients approaching the end-of-life care, where patients should be actively included in treatment decisions (The Scottish Government, 2008, 2015).

For educators, the importance of unambiguous, consistent language has been emphasised. Multiple terms may cause confusion for learners (Graham et al., 2006; Bausewein and Higginson, 2012). Within end-of-life education, the need for clear learning outcomes has been identified (Linklater, et al., 2014), however outcomes-based education requires constructive alignment of outcomes, learning activities, and assessment, in which the material under study is clearly explained (Biggs, 1996; Schuwirth and van der Vleuten, 2010). The present study should call us to question any teaching and assessment which requires students to present concepts as

straightforward and clearly defined, when this does not reflect the complexities and subjectivities of clinical practice.

3.5.3. Strengths and Limitations

The scoping study benefited from its clear and replicable design. The search strategy was systematic, robust, and guided by language found in the literature from its earliest stages. The search strategy yielded a broad sample of language used in discussion of UK medical practice, as the sample includes varied documents types, from a variety of publishing sources, which discuss a wide range of patient ages and disease types (see Table 5). The QCA of included data went further than the analysis generally possible in a scoping study and allowed for analysis of heterogenous data sources. This has led to a significant contribution to the existing literature (described above). However, it is important to be cognisant of potential limitations.

Limitations of the study included the impossibility of obtaining the full text for all search results, although only 22/3296 (0.67%) were excluded because the full text was unobtainable. Scoping studies do not include consideration of quality, and documents which met the inclusion criteria were considered regardless of their quality, although this study analysed only language used, making documents relevant regardless of quality. Furthermore, I included terms in the analysis regardless of how frequently they appeared, because I sought to explore the breadth of concepts rather than those most commonly used.

This study only considered the approach to the end-of-life in the context of death which could be anticipated, therefore no emergent concepts related to rapid onset or traumatic conditions in otherwise healthy individuals. I consider this to be acceptable

for a UK context, as the majority of deaths in Western countries follow a chronic illness, such as heart disease, cancer, stroke, or dementia (Hyde, Skirton and Richardson, 2011).

Furthermore, the scope of included documents was limited to the UK, as medical language varied too widely between health services or cultural contexts to lead to useful analysis. Furthermore, I am a British practitioner-research based in the UK, therefore my interpretation is grounded in thorough knowledge of UK medical practice. These factors limit transferability of findings to non-Western contexts, although do not undermine the overall goal of this UK-orientated thesis.

Although it is my belief that terms in use are acceptable and understood by UK medical doctors, there will of course be further language in common parlance in the healthcare system which is not captured here. QCA does not assume objectivity (Elo and Kyngäs, 2008) but I aimed to achieve findings which can be inter-subjectively understood. I have not yet tested the results outside the scope of this, although many scoping studies do not include this stage (Stage 6 of SSM; Table 3). Future research may incorporate consulting medical doctors at different stages of their training (i.e. junior doctors and consultants) and careers to enrich and/or challenge the conceptions emerging from this QCA.

It is important to make clear these conceptions come from the perspective of medical doctors. Social construction of medical knowledge has been criticised as exerting power imbalance over patients (Conrad and Barker, 2010). This can be seen clearly as the approach to the end-of-life in the ‘Care of the patient’ category consider this in terms of the actions and work of doctors, but even in the ‘Patient and the illness’ category, concepts of the effects on patient are considered from the perspective of

the doctor. The patient her/himself is likely to have different perspectives on the effects of their condition on their life, and construct meanings differently. Understanding how medical doctors conceptualise the approach to the end-of-life therefore does not necessarily advance our understanding of how patients conceptualise this. The categorisation and construction of medical knowledge that occurs among medical doctors may be harmful or limiting to patients, including in cases where patients are dying (Kitzinger and Kitzinger, 2014). This can make it more difficult for patients and/or their families to make sense of their experiences. In other words, as the analyst, I am myself a medical doctor, meaning the results are the words of doctors interpreted by a doctor. Future research should consider conceptions of the approach to the end-of-life through the lens of the patient.

3.6. Conclusions

This chapter has demonstrated differences in conceptions of the approach to the end-of-life among doctors. The importance of doctors learning to understand the approach to the end-of-life is affirmed in the literature, however analysis demonstrates there is no linear, single means by which this is achieved, indicating a challenge for medical professionals. Understanding the approach to end-of-life is not a single disembodied way of knowing but is constructed by medical doctors in subjective ways linked to their practice. This chapter has therefore further situated this thesis within socio-material learning and considering education as linked to workplace practice. In order to further explore the learning of medical doctors, it is

necessary to consider the experiences of medical doctors learning in the workplace, as will be expanded on in the following chapters.

4. Qualitative research interview methodology and methods

4.1. Introduction

The next findings I present in this thesis were generated using qualitative interview methodology. This research will correspond with the research aims of examining how the approach to the end-of-life is conceptualised by medical doctors, and exploring experiences and understandings of doctors learning to care for patients at the approach to the end-of-life, including factors which provide barriers to learning Analysis of the data was undertaken using inductive thematic analysis. The results of analysis are presented in Chapter 5. This chapter explains the methodology and methods employed.

4.2. Qualitative Research Interviews

I conducted research interviews with foundation doctors, i.e. in their first two years of postgraduate training. The interviews explored how foundation doctors experience, perceive and understand patients' approach to the end-of-life. Foundation doctors were selected for study because they have recently made the transition from being medical students into clinical practice as doctors. Based on this background understanding, I determined they would provide useful insights about entering the workplace and how prepared new doctors are for this area of practice.

Research interviews are the dominant means of data collection in social research (Silverman, 1993), but may be carried out in numerous ways, e.g. highly structured, partially structured or completely unstructured; from paradigms of positivist, critical theorist, post-modern, realist (Edwards, et al., 2014a). This section will explain how I have conceptualised the research interviews, how the interview dynamic has affected data generation, and the importance of reflexivity in this process. I have also published a detailed methodological discussion of my approach to qualitative research interviews elsewhere (Qureshi and Rankin, 2019) – see Appendix 7.

4.2.1. Conceptualising the research interview

Qualitative research interviews allow the study of phenomena experienced by individuals, the meanings of these phenomena to participants, and accounts of how these phenomena came into being (Brinkmann and Kvale, 2015). In-depth, semi-structured interviews are distinct from structured interviews and questionnaires with pre-determined domains of response. Exploring the perceptions of individuals inevitably leads to fluid and idiosyncratic responses. Responses cannot be pre-defined and anticipated, unlike structured interviews or questionnaires. The semi-structured interview allowed me develop an interview schedule in advance based on my starting understanding of the area of interest (from existing literature and my own experiences as a junior doctor), to guide the structure of the interview. However, each interview progressed in unique ways, meaning the valuable questions to ask were defined by the interviewer and the participant during the process. This is contrary to traditional clinical science which favours reproducibility and objectivity.

My view is that as interviews progressed, I was not uncovering objective truths that were waiting for me to reveal them. Instead, the interviews were social interactions, during which explanations and feelings were interpreted in dialogue, and so meanings were co-constructed between the participants and me (Crotty, 1998; Hammersley and Atkinson, 2003). Data was therefore actively generated from qualitative research interviews. Knowledge was not generated only during each interview but continued after the interview through the interpretation, analysis and writing (Brinkmann and Kvale, 2015).

I was not only seeking to explore and generate subjective meanings. Critical realism (CR) seeks to reach a theoretical explanation for the social world. CR researchers accept that some views of the world are more accurate than others, i.e. judgemental rationality (Edwards, et al., 2014b). It is essential that data generated is considered within the wider social world (Edwards, et al., 2014a). During the interviews, I probed participants to reflect on processes which have caused them to have their experiences. This allowed for phenomena to be considered as situated within their contexts. Nevertheless, it important to be mindful of the limits of subject qualitative research interview when making claims about the transferability of the findings to other times and places (see section 4.3.3).

4.2.2. Interview Dynamic

Data generation in this study occurred through conversations between foundation doctors and me. In conducting the research, I took on the role of a practitioner-researcher, i.e. undertaking systematic investigation relevant to my own work

(Robson, 2002). I believe my questions were framed with a greater first-hand understanding of the issues discussed, and participants likely contributed to the conversation in a way they would not have done had I not been a junior doctor. This allowed me to frame the interviews as a conversation between peers. These could be viewed as a form of peer interviews, which have been widely discussed in the research literature. However, peer interviews are most commonly described as those when a researcher commissions someone else to perform the interviews and generate data upon which the researcher performs analysis separate (Devotta et al., 2016). In contrast, in my case, I was an insider to the area under study, who conceived, designed and conducted every step of this research about my own work environment.

It was, however, important that participants saw me as on an equal level, and I endeavoured to reduce any power. Medical training culture is hierarchical and competitive (Lempp and Seale, 2004), however I did not work directly with any of the participants (nor know any of them personally) and the voluntary nature of the interviews was emphasised. These interviews involved discussion of times when patients had deteriorated and died, and my experiences as a doctor allowed me to understand they may be personally affecting for the participants. For this reason, I chose the one-on-one interview format in preference to focus groups or group-interviews, so that participants could speak more freely about their experiences, thoughts and feelings, away from their colleagues. The interviews gave participants the opportunity to discuss their experiences, and feelings about them, in a space where they could be honest and feel listened to, and I aimed to cultivate a judgement-free attitude. Although this was a potentially cathartic experience, it was not appropriate for me to offer emotional support or guidance. Participants were offered

optional pastoral and professional support from medical doctors not linked to the study.

Furthermore, I understood that participants may be concerned about the content of their interviews being made available to people in a position of power over them such as educational supervisors and line managers (Dennis et al., 2012), which may cause particular concern if they were critical of their superiors and/or their workplace. I recognised it as important to reassure participants that all interview data would be anonymised and that only I would know the true identify of any participant. Participants were assured their participation or non-participation would not affect their employment or training (see Section 4.4 below).

Despite being a peer to participants and an insider to the area under study, it was important for me to be open to have my preconceptions challenged and not impose pre-established meanings onto the interviews. In order to do this, I endeavoured to phrase questions as open and slightly ambiguous, in order to allow the interviewee to speak as naturally as possible. In the data analysis, I also endeavoured to demonstrate reflexivity to maintain the trustworthy of this research.

4.3. Qualitative Data Analysis

Data analysis is the most complicated and demanding aspect of qualitative research (Nowell et al., 2017). This section discusses methodological issues related to my analysis of the qualitative interview data. It will begin by describing the inductive analytical process which I undertook. It will then discuss issues of rigour of this research, including reflexivity.

4.3.1. Thematic analysis

Thematic analysis (TA) is a form of qualitative data analysis which seeks to identify themes within data. A theme is a pattern or message within the dataset which captures something important in relation to the research question. TA allows the researcher to examine perspectives of participants and illustrate similarities, differences and summarise the key findings of a large data set (Nowell et al., 2017). Themes are not quantifiable, but are important message conveyed in data. There is not an established straightforward correlation between prevalence of a theme in the data set and it being an established theme. Themes should not be generated purely based on a few vivid examples, but after ensuring data has been examined thoroughly and comprehensively in order. Researcher judgement is necessary to determine what constitutes a theme (Braun and Clarke, 2008).

TA is not specifically restricted to one philosophical or methodological tradition. It is widely employed in qualitative research due to its flexibility and modifiable nature. TA may occur as part of a wider methodological process, but it has been asserted as a its own methodology (Nowell et al., 2017). In response to widespread and inconsistent description of TA (Tuckett, 2005a), Braun and Clarke (2008) have defined a widely cited framework for researchers to follow. I have summarised these stages of analysis – and the steps I took to align my analytical process with this framework in Table 7.

Table 7. Stages of Thematic Analysis, adapted from Braun and Clarke (2008)

Stage of Analysis Process	**Description of stage as related to this study**
1. Familiarisation with data	Listening to recorded data, reading and re-reading written data, making preliminary notes
2. Generating initial codes	Noting meanings within data and coding for these, gathering data relevant to each code
3. Searching for themes	Reviewing codes and collecting them into potential themes. This continues until all data fits into potential themes.
4. Reviewing themes	Comparing themes to the raw data and across the dataset
5. Defining and naming themes	Analysis of each specific theme until they are each defined, and the overall story of the analysis is clear
6. Producing the report	Written presentation of the themes as a congruent story, with selection of representative extract examples and discussion of how they relate to the analysis.

Although presented as discrete stages in the TA process, the process was iterative with toing-and-froing between stages, and analysis occurred concurrently as interviews progressed. I began with becoming immersed in the data (Stage 1). I started to identify codes in the data, i.e. a word or short phrase which "symbolically assigns a summative, salient, essence-capturing and/or evocative attribute for a portion of language [..] based data" (Saldana, 2015, p.4). Coding involved interpretation and judgement on my part. Different coding approaches exist , but initial coding approaches (Stage 2) I used were principally *in vivo* codes – those which use words of the participant's own language in order to prioritise and honour the participant's voice – and process codes – those which use gerunds to reflect dynamic actions and interactions (Saldana, 2015). As my interpretation progressed, codes made it easier to navigate the messages contained within the data, and I defined the relationships between codes. This allowed me to iteratively categorise them into themes (Stage 3). I contrasted these themes against the raw interview data in order to refine them (Stage 4). As this progressed, I further categorised themes as sub-themes, i.e. containing important thematic messages related to over-arching themes.

After I completed Stages 3 and 4, another researcher external to this study (Dr Neill Storrar (NS)), reviewed a sample of my raw (anonymised) data set in order to separately generate codes and initial themes. NS is also a physician and researcher in medical education but was not involved in the design or conduct of this study. NS's analysis occurred separately from mine, did not influence my analysis, and has not been included in my results. Instead, NS's input served as a form of triangulation. Varied definitions of triangulation exist (Varpio et al., 2017), but in this context I mean confirmation of trustworthiness: that my analysis correlates with the data in an understandable way, and that I have not imposed meanings on the data which cannot

reasonably be agreed to have been generated organically (Mcevoy and Richards, 2006). After NS and I reviewed our respective analyses, we agreed that my analyses could be sufficiently verified from the data (Nowell et al., 2017). The analysis conducted by NS was then discarded and not incorporated into the remainder of this research process.

In Stages 5 and 6 I established demarcations between sub-themes and themes and wrote explanations of which each theme represents. This naturally led into the writing of the study results which then became integrated into the construction of this thesis. Stage 6 of analysis has continued as I examine the meanings of my results.

TA may variably involve pre-established frameworks to aid analysis (Smith, Bekker and Cheater, 2011; Nowell et al., 2017). I coded inductively and did not incorporate such a specific framework, which aligns with the exploratory nature of this study and my aim of allowing findings to honour the experiences of the participants rather than pre-conceived ideas. Applying pre-defined coding rules may have limited the possibility of context and participant-sensitive interpretation (Yardley, 2000). However, my analysis was sensitised (Bowen, 2006) by existing theory and literature. This includes cognisance of my underlying socio-material perspective, and Cultural Historical Activity Theory (see Chapter 6).

4.3.2. Ceasing data generation

Primary data generation ceased after fifteen semi-structured interviews were conducted. As this is qualitative research the number of interviews required is guided by the value of the meanings generated, rather than quantitative considerations

(Baker and Edwards, 2012). Discerning the correct number is a recognised area of challenge (Malterud, Siersma and Guassora, 2015). Often qualitative researchers state that they stopped undertaking new interviews after (data or theoretical) "saturation" occurred. This concept was originally devised as part of Grounded Theory Methodology (Glaser and Strauss, 1967) – which I am not using – but is now widely used to denote a research stage where further data generation is not contributing anything new to analysis. Saturation is considered by some to be a sign of academic rigour (Varpio et al., 2017). However other researchers – including me – question whether absolute saturation is possible, and feel that ubiquitous use of the concept of saturation is inappropriate (Reilly and Parker, 2012). As I have asserted above, I consider the research interview to be unique, dynamic data generation process in which participants respond in irreproducible, idiosyncratic ways and meanings are negotiated between the researcher and participant. Every individual will have a different perspective, therefore I find it unrealistic to conceive a time when more interviews will not lead to new insights.

I found it more useful to consider whether there was adequate data to meaningfully answer my research questions. This corresponds with the concept of information power (Malterud, et al., 2015), i.e. the more information held by the sample, the fewer participants required. The number of participants required was determined iteratively as interviews and analysis progressed. I found that the data generated was rich and allowed for valuable analysis. Given my epistemological position that I am seeking to find a robust theoretical explanation for the learning and understandings of doctors rather than lead to generalisable findings, I obtained sufficient data for this stage of analysis, and upon which to apply further theoretical analysis (Chapter 6).

4.3.3. Maintaining rigour

Maintaining rigour throughout analysis is important to ensure research trustworthiness. In Chapter 2 I introduced Lincoln and Guba's (1985) framework to evaluate the trustworthiness of qualitative research. This provides a suitable framework to consider elements related to the trustworthiness of this TA study (Nowell et al., 2017):

- **Credibility** (confidence in the findings fitting with the data): participants undertook member checking of the written transcripts to ensure that it provided a fair representation of the data generated during the interviews. As described above, another researcher (NS) carried out a separate analysis, as a form of peer de-brief to check the research process and triangulate interpretations of raw data. Furthermore, in achieving management approvals for this study there was an external check that all study materials and plans for data management were robust (see below section 4.5.2). In my analysis I have also drawn attention to atypical cases and data which does not fit with the overall theme.
- **Transferability** (applicability of findings to other contexts): participants in this research were recruited from one relatively small geographic location (South East Scotland) but were undergoing a UK-wide national training programme and had graduated from eight UK medical schools (Table 8). Based on how the results compared with existing literature, I believe that the workplace experiences of my participants are comparable to foundation doctors undertaking training in other locations. I have provided details of the experiences of participants, to allow the reader to ascertain applicability of findings to their own context (Tuckett, 2005b).

- **Dependability** (findings are consistent): I have maintained comprehensive documentation of every step of this research and have provided detailed accounts. This includes providing explanations for the research decisions I have made, and discussion of the limitations of my processes (Section 4.7). Although my research is irreproducible, I have provided sufficient information for another researcher to reasonably follow my process and understand how I reached my findings.
- **Confirmability** (neutrality allowing the findings to be generated from the data rather than research bias): In presenting my findings I discuss and explain how the claims I make have been derived from the data. I took measures to ensure I was not imposing meanings on the data which did not stray from its original meanings: initiating my coding process with language used by research participants (*in vivo* codes); utilising an external coder (as above); processes to maximise reflexivity, as described below.

Reflexivity is a further quality control issue central to qualitative research (Malterud, 2001; Finlay, 2002). I acknowledge that my underlying values and beliefs have influenced every aspect of this research (Greenbank, 2003). Chapter 1 has provided some information about my background and the pre-conceived ideas which led into design and conduct of this work. Furthermore, in data generation and analysis during this study, I aimed to be conscious of my own views, and strove not to impose on to the experiences of others. To achieve this, I maintained field notes after every interview; reflexive diaries throughout the analysis process. These captured my thoughts and feelings in relation to the data generated and aided me in reflecting on which data surprised or challenged me, and why. Nevertheless, one can never be fully cognisant of one's own pre-conceptions and biases. Lack of awareness of all

my own biases is made more likely by the fact that I was a member of the same professional group as the study participants: tacit conceptions of norms and influences on individual behaviour in the workplace will exist, some of which may be unconscious (Sukhera et al., 2018).

Ultimately quality control of the research rests in the completeness of data and analysis, and integrity of the researcher (Reid et al., 2018). As with all elements presented in this thesis, I have endeavoured to provide as transparent and detailed picture of my work as possible. This will allow the rigour of the work to be appraised, and the value of my claims to be evaluated.

4.3.4. Building theory from the findings

CR research aims to find the best theoretical explanation (Edwards, et al., 2014b). Although results of the thematic analysis are presented in Chapter 5, further analysis involving employment of Cultural Historical Activity Theory as a theoretical framework will be presented in Chapter 6.

4.4. Ethical Considerations

It is necessary to consider the potential benefits of the research, the potential negative effects, and to weigh up and balance between these. NHS Research Authority's (2018) Framework for Health and Social Care Policy identified salient issues for ethical and scientifically sound research including safety, informed consent, confidentiality, secure data management, legality, quality and transparency.

I have described above trustworthiness issues, which are also important for conducting ethical research.

This interview study presents additional and specific ethical challenges. At the recruitment stage, I was aware that junior doctors have multiple other commitments. The time and place of interviews was planned thoughtfully to accommodate the participant and avoid times participants were likely to be excessively tired.

During the consent process, participants were given the opportunity to make informed decisions about whether to participate, having the advantages and disadvantages clearly explained. They were provided with comprehensive written participant information in advance and invited to ask questions. I explained the only direct benefit to the participant was the satisfaction of having contributed to research. However, being an interview participant can be richly rewarding (Corbin and Morse, 2003) and discussing challenges at work to another doctor with an inside knowledge of the system, in an anonymous way, may have provided cathartic benefit to some participants.

The main disadvantage for participants is the time and effort, when their time is already limited. Also, topics addressed may have been personally emotionally difficult for participants. Participants were given the opportunity to approach a named senior doctor who is independent to the study to discuss challenging personal and professional issues raised.

Maintaining confidentiality and anonymity of participants was also important. Participants were made aware that extracts of anonymised data and results of analysis would be available to others, but their identity would not be revealed. There would be no workplace or training repercussions for what was revealed during the

interview, except for one important caveat: if they raised significant concerns for patient safety then this would need to be escalated within the health service, which would likely result in their identities being revealed.

The subjects may have felt under scrutiny and resulting in power asymmetry (Clancy, 2013). Such power asymmetry may be accentuated within medical training. I endeavoured that participants did not perceive any pressure by not recruiting any participants with whom I work directly or know personally. During the interview I attempted to give participants counter-control by being receptive to their meanings and checking my interpretations of what had been said. I also asked participants to review transcripts in order to ascertain they were comfortable with the content proceeding to analysis. Before, during and after the interview, participants had the opportunity to withdraw their participation or ask for part of the data to be redacted. Participants were also given details of who to approach should they have concerns about my conduct or the study generally.

4.5. Methods

4.5.1. Recruitment

Doctors undergoing foundation training in South East Scotland (NHS Lothian and NHS Fife) were invited by e-mail to volunteer for participation in this study. They were asked to contact me by individual e-mail if they were interested in taking part so no one else would be aware they were participating. They were informed they could contact me for further information without committing to participation.

The recruitment e-mails were sent by the medical education department in each health board. This protected confidentiality by avoiding me having direct access to the doctors' personal contact details, unless they chose to contacted me directly. The e-mail contained participant information (see Appendix 2). A reminder email was sent out two to three weeks later.

When a potential participant contacted me to participate, a mutually convenient time was agreed, out with the participant's normal working hours. Each interview was held in reserved meeting rooms which were separate from clinical areas, and with only the participant and me present.

4.5.2. Ethical and Clinical Management approvals

This study received research sponsorship from University of Edinburgh Academic and Clinical Central Office for Research and Development (ACCORD). The study was granted management approval by NHS Research and Development (R&D) offices in Lothian and in Fife, which was co-ordinated by the NHS Scotland Permissions Co-ordinating Centre. The need for formal NHS Research Ethics Committee (REC) was waived as no patient data was collected (NHS Health Research Authority, 2018). Nevertheless, all aspects of this planned research were scrutinised, including processes for informed consent, data management and confidentiality. Dr David Hope, University of Edinburgh, provided an independent research ethics opinion as he is a medical educationalist who was not involved in the study.

4.5.3. Informed consent

The meetings began with a review of the participant information and the participant had the opportunity to ask any questions before continuing. If the participant agreed to continue as part of the study, s/he completed two copies of a comprehensive consent form (see Appendix 3). One copy was given to the participant for his/her own records, and one copy was retained by me. As part of the consent process, the participant was informed of her/his right to withdraw from the study at any point after the interview, without giving a reason.

4.5.4. Data Generation

Data were generated through semi-structured interviews with the participants. The interviews began following a similar initial structure from an interview schedule, where the participants were asked about experiences of clinical care at times when patients deteriorated and died. The interviews diverged depending on the data (see Section 4.2). Interviews were recorded to maximise the record of the interview was as accurate as possible. This allowed for generation of verbatim transcripts on which to conduct analysis. Although I informed participants that recordings would be held confidentially and stored securely, the recording process may have made participants feel inhibited about what they divulged. I cannot exclude the possibility that deciding to record the interviews limited the completeness of the data generated.

4.5.5. Transcription and Data Management

Each participant was assigned a pseudonym. Recordings were stored securely in a password protected folder on the University of Edinburgh secure server. The recorded interviews were transferred to a reputable private secretarial service securely. No identifiable material was attached to these recordings. The secretarial service transcribed the interviews and provided me with the initial written transcript. I reviewed each transcript and the corresponding recording in order to correct any mistakes, and ensure no identifiable information was included. Each transcript was then sent to the corresponding participant, who could ask for data to be redacted, or for any corrections if they perceived there to be errors. After each written transcript was agreed, they were stored securely on the University of Edinburgh server. Only the participant's pseudonym is attached to each transcript. The real identity of each participant is known only to him/her and to me.

4.5.6. Analysis

Thematic analysis is described in detail in Section 4.3.1. The computer software programme *NVivo 11* (QSR International, 2015) was used to manage the analysis electronically.

4.6. Participants

Fifteen foundation doctors were recruited to this study. Table 8 below presents: details of the foundation doctor participant (by pseudonym), site of undergraduate medical degree, grade at the time of interview (FY1: first post-graduate year; FY2: second post-graduate year), and time since graduation by date of interview.

Table 8. Interview study participants

Name	University of undergraduate training	Grade	Time since graduation (months) on date of interview
Charles	Edinburgh	FY2	21
Catriona	Edinburgh	FY1	9
Zach	Glasgow	FY1	9
Marta	Aberdeen	FY1	9
Jonah	Edinburgh	FY2	22
Eve	Imperial College London	FY2	22
Cassie	Manchester	FY2	22
Harry	Edinburgh	FY2	13
Rosie	Edinburgh	FY2	13
Tanya	Edinburgh	FY2	14
Scarlet	Brighton and Sussex Medical School	FY2	14
Theo	University College London	FY2	14
Victor	Edinburgh	FY2	15
Lukas	Cambridge	FY2	15
Camille	Glasgow	FY2	27[3]

[3] The Foundation Programme normally lasts 24 months but note Camille's longer time since graduation. This was due to a period of sick leave which resulted in extended training.

4.7. Limitations of design

It is important to acknowledge the limitations in the study design. Firstly, there are limitations related to the sampling of participants. Qualitative researchers may incorporate theoretical sampling, i.e. planning the sample to pursue certain conceptual ideas rather than seeking general information (Bagnasco, et al., 2014). To an extent, I have incorporated theoretical sampling: my background understanding led me to understand foundation doctors were likely to have valuable insights on workplace influences on learning. However, I did not further limit the scope of recruitment. Seeking to recruit specific individual doctors would have been against my ethical commitment not to pressure doctors, and conflicted with my inductive, exploratory approach.

Participants were volunteers, and their choosing to do so likely depended on various factors including enthusiasm for the topic, having strong opinions or negative experiences, and having availability around work and other commitments. They may not have been indicative of experiences of others. However, I am not making claims of generalisability, and furthermore, believe that that every person is likely to have different perceptions. I am seeking to explore what factors affect the developments of understandings and the workplace and develop a theoretical explanation of explain phenomena. Moreover, I have provided sufficient information to allow transferability to be judged: the participants are undergoing a national training programme and working in a health system which is common across the UK, and the clinical and workplace issues they face do have commonalities in other settings. The reader can judge how the findings may or may not transfer to their own context (Tuckett, 2005b).

Data generation may have been limited by only being contained to one individual interview. Although participants were asked to internally reflect on issues related to topic (and participant information) prior to the interview, they were not required to have prepared in advance. Participants were busy practitioners with multiple commitments, and I believe it would have been impracticable and onerous to expect them to complete work in advance, e.g. written reflections. It was therefore during the interviews that I probed participants to and reflect on their experiences, which allowed rich data generation but took time. This perhaps missed capturing experiences and insights which may have been gained had participants been actively thinking about the topic of study for longer.

The analytical approach can also potentially be criticised. TA is useful because of its flexibility, not being bounded to any methodological tradition (Tuckett, 2005a). This aligned with the exploratory and inductive nature of this research. However, it has also been criticised as atheoretical and superficial. For example, I consider how the approach-to-the end of life is conceptualised, however TA does not facilitate a detailed analysis of language used, in contrast to other methodologies such as discourse analysis, and so consideration of language itself has not contributed to my findings. Furthermore, a coding framework may demonstrate trustworthiness in TA (Nowell et al., 2017), but as I have explained (Section 4.3) I did not perform the TA with a pre-established framework. However, I have carried out further analysis which grounds the findings in a framework (Chapter 6)

One further potential criticism is that it was conducted by a novice researcher, by the nature of this study being carried out as doctoral work. Qualitative interviews may be seen as a craft, with skills researchers must develop over time (Brinkmann and Kvale, 2015). I believe my research skills as both an interviewer and data analyst have

developed over time. This involved consciously adopting a different style of interviewing from my clinical practice, i.e. different from gathering clinical information from patients; from questioning students during medical teaching. I sought for participants to be open about their experiences and feelings, rather than provide facts. This involved learning to word questions out of a genuine curiosity to learn the answer (Liamputtong Rice and Ezzy, 1999).

I was required to adopt a different perspective from the traditional positivist view of science which is most commonly adopted in clinical medicine. Such a change in analytical thinking has been described as 'learning to think qualitatively' (Hunt, et al., 2009). With prolonged engagement and persistently immersing myself in the data I progressively developed skills in data analysis. Certainly, if I was to conduct this study again now, I would have been able to do so more efficiently, but I have developed as a researcher through completing this process, and believe that despite being a novice researcher I have generated valuable results.

5. Experiencing patients approaching the end-of-life - Results from qualitative interviews with Foundation doctors

5.1. Introduction

This study fulfils the research aim of exploring experiences and understandings of doctors learning to care for patients at the approach to the end-of-life, including factors which provide barriers to learning. Additionally, with Chapter 3, it contributes to addressing the research aim of examining how the approach to the end-of-life is conceptualised by medical doctors.

5.2. Results

Analysis led to generation of five over-arching themes: perceptions of patient care (with four sub-themes); understanding the approach to the end-of-life (with three sub-themes); role of the doctor (with three sub-themes); preparation for the role (with two sub-themes); influences on workplace learning (with four sub-themes). The themes are explicated in detail in the following sections and data extracts are presented as representative examples. For clarity, the over-arching themes and sub-themes are presented in Table 9.

Table 9. Themes generated from analysis of interview data

Over-arching themes	**Sub-themes**
Perceptions of patient care	Expectation of cure Becoming palliative Decision making Quality of patient care
Understanding the approach to end-of-life	The patient Implications of treatment Imagining self
Role of the doctor	Being junior Role of the foundation doctor Tensions in the role
Preparation for the role	Adequate preparation Inadequate preparation
Influences on workplace learning	Nurses Organisation Time and experience Emotional reactions

5.2.1. Perceptions of Patient Care

All FY participants described experiences of caring for patients who did not recover from their illness. These descriptions allowed analysis of the participants' understandings about the care received by the patient, perceptions of the quality of this care.

5.2.1.1. Expectation of cure

> Zach: "My job is to make people who are not well, better." *(FY1, 9 months since graduation)*

Participants described the notion that the normal expectation of the patient and medical team would be of cure. Patients were not cured if medical treatment was ineffective or unavailable.

> Victor: "When a person comes into hospital the general expectation is that we're going to try and make things better and I think that should be your default. But sometimes [..] further down the line you realise that it won't work. It won't be in their benefit." *(FY2, 15 months since graduation)*

From this perspective, care of the patient has fulfilled its purpose when patients are cured. Participants varied in the proportion of medical care which they believed to

be successful. Some indicated they believed that it is rare for patients not to be cured.

> Shaun: "So what kind of proportion of patients [cannot be cured]?"
>
> Victor: "Oh, less than five per cent. Less than two and a half per cent." *(FY2, 15 months since graduation)*

In contrast, others believed the majority of patients are not cured.

> Eve: "I think generally only children really get back to a healthy state. [..] You're trying to get the patient back to their baseline, but you're not really getting back to full health." *(FY2, 22 months since graduation)*

The possibility of a patient not being cured and/or dying had not been made explicit before commencing postgraduate training. Participants described having started work with the expectation that patients would be cured most or all of the time.

> Rosie: "By the end of my rotation I'd be like, 'well, I don't think they're going to survive', whereas at the 'beginning I think I would have thought, oh, they're going to have surgery and fix it'." *(FY2, 13 months since graduation)*

The development of this understanding was displayed when participants looked back on their earlier work experiences. Participants reflected on instances they had not been able to recognise the patient would have deteriorated and died.

> Camille: "I think I had gone in with the expectation that I was supposed to make her feel better that day and nothing I was doing was having a great deal of effect and then suddenly she was dying. I think if I'd gone into that thinking, 'this woman feels very unwell, she might be dying' [..] then that would have been a very different approach." *(FY2, 27 months since graduation)*

This indicates an initial expectation for interventions to lead to patient survival. With this modified view, prior experiences of pursuing ongoing treatments for certain patients were now seen as futile and potentially harmful.

> Marta: "He went to [High Dependency] I think, I didn't really change anything for him. Possibly it would have been better for him to stay on the ward with the staff, with him and the family to stay in his room." *(FY1, 9 months since graduation)*

Furthermore, having developed the understanding that cure was not expected for some patients, participants could now anticipate this for patients.

Lukas: "I wasn't sure why they kept going for so long, why we had to wait for eroding vessels before we had a conversation about 'we can't really do much for you'." *(FY2, 15 months since graduation)*

This caused feelings of frustration if there was no acknowledgement of this within the medical team, or communication of this to the patient and their relative.

Catriona: "It does make me wonder, is it for the benefit of the patient that we're continuing treatment, or is a benefit for us, because we desperately want you to get better. It does make us feel great when somebody gets better, and it's horrible when someone dies." *(FY1, 9 months since graduation)*

Experiences where they felt patients were inappropriately treated with curative intent led to anxiety and confusion among the participants in some cases.

5.2.1.2. Becoming palliative

> Jonah: "I think care becomes palliative whenever you have decided that you are not attempting to provide curative intervention." *(FY2, 22 months since graduation)*

In cases where cure was not achieved, there was a perception of a change taking place. Participants described this as a process of 'becoming palliative'. Often, it was conveyed that it was the *care* delivered which had now 'become palliative'.

> Cassie: "So, end-of-life care, palliative care, just for, like symptom control, making them as comfortable as possible. They're aware that it's not going to cure them, but just to make them comfortable." *(FY2, 22 months since graduation)*

There was no precise explanation of "palliative care" from any participant, but generally this term conveyed care when the goal was no longer cure. This was not routine care, but something had happened to change the goal of care. The term "active treatment" was sometimes employed as contrast. Active treatment denoted aiming to alleviate illness.

Zach: “We like to use the term active treatment, especially when you're talking to relatives. Essentially, to clarify to the patient and relatives that we are having this discussion so that we know what you want, in terms of what we should do in case your condition gets worse, or if your heart stops.” *(FY1, 9 months since graduation)*

The line between palliative treatment and active treatment was not always clear, and at times the patient appeared to be receiving both.

Catriona: “There has been a few times where it’s been overlapping, and that was quite a lot on [geriatric medicine], where you’re actively treating, yet the person is on palliative medication.” *(FY1, 9 months since graduation)*

The lack of clear demarcation between palliative care and active treatment could cause difficulty determining the correct course of action.

Marta: "I once saw a patient again on a weekend who was end stage palliative lung cancer and becoming more breathless [..] but when I saw him, he had a temperature, he was breathless, so I trawled investigations, he had worsening aspiration and wasn't quite sure what would be appropriate to do in that situation." *(FY1, 9 months since graduation)*

In other instances, it was not the care, but the patient him/herself who was considered to 'become palliative'.

Eve: "He did eventually become palliative [..]" *(FY2, 22 months since graduation)*

The word "palliative" was not always used, and in some instances other terms were used to convey similar ideas, e.g. TLC (tender loving care).

Shaun "And what do you mean by 'made TLC'?"

Lukas: "It was decided the focus of care now is not to stop the bleeding or to cure her. It was that the focus is to make her as comfortable as possible." *(FY2, 15 months since graduation)*

This change to ‘becoming palliative’ was mostly described as occurring in one direction: most patients who ‘become palliative’ went on to die in hospital or be discharged to home to die. However, there were some instances when patients who ‘became palliative’ did later go on to recover or have a better clinical course than expected.

> Harry: “I can think of a couple of examples, severe infections and sort of GI bleeds, where things have settled down and families have been told, actually I don't think this is going to go very well, the patient’s starting to get better.” *(FY2, 13 months since graduation)*

Eve recounted a case where, in her view, a patient who had been ‘made palliative’ subsequently changed to no longer being ‘palliative’. The patient had been expected to die, but made an unexpected recovery:

> Eve: “I guess there was a little bit of *umm-ing* and *ahh-ing* because me and the other junior could see that she looked a bit better. But it’s difficult when someone’s been made palliative because you don’t usually see them getting better. But, a couple of days later the consultant said I think we should do bloods on this patient again, which you wouldn’t do for a palliative patient. We did them and actually they were plum normal.” *(FY2, 22 months since graduation)*

From Eve's account, it appears that after 'becoming palliative' it is not usual to carry out investigations. Eve was left unsure of the correct course of action after the 'palliative' patient showed signs of recovery.

5.2.1.3. Decision-making

The change towards 'becoming palliative' occurred through a process involving evaluation, discussion and decision making.

> Zach: "They've been properly assessed, and it's been decided, after elaborate discussions between the patient, the family, and the team, that nothing more can be done for this cancer." *(FY1, 9 months since graduation)*

For patients who were going to die, the doctor having decided to the patient or their care is palliative was regarded as positive, and important for facilitating a good death. Good (or better) deaths are not exactly defined in the data but are those, for example, where there was advance recognition the patient was dying, where invasive treatments were discontinued, and when the patient and their relatives were aware the patient was going to die. Correspondingly, cases where patients died without such a prior decision were viewed negatively. These cases tended to result in patients receiving attempted CPR at the time of death.

Harry: "A lady in her late 90s who clearly had end stage disease. There was lots of mention, reading back through the clinical notes about the need for DNACPR discussion, and we were called to this woman when she'd arrested, spent 45 minutes performing CPR, putting lines in. When her family arrived, they were horrified to see that. They were actually quite upset that no one had ever given the opportunity to say no." *(FY2, 13 months since graduation)*

CPR was perceived as particularly negative and a failure of adequate decision-making. This led to frustration when this did not happen.

Lukas: "The talk between doctors was that she's definitely going to die [..] and although it was mentioned that we need to think about discussing with all honesty what's going to happen, I think no-one really wanted to because she didn't seem very on board with how unwell she is." *(FY2, 15 months since graduation)*

Participants described decision-making involving interactions between doctors, between doctors and the rest of the healthcare team, and, to some extent, between the healthcare team and the patient and their relatives.

Jonah: "Obviously, ultimately, it's the consultant's decision. But it was definitely a team decision [..] between the medics, the nurses and the patient, plus or minus whoever else was potentially involved." *(FY2, 22 months since graduation)*

Ultimate responsibility for decision-making generally rested with the consultant. In most participants' experiences, the consultant considered the opinions of her/his colleagues. Participants described forming opinions about whether a decision should be made that the patient had 'become palliative'. Some felt they were included in decision-making, and that they could contribute to discussions, but others were not involved.

Shaun: "Do they ask you what you think?"

Marta: "No."

Shaun: "And do you ever voice to them what you think?"

Marta "No" *(FY1, 9 months since graduation)*

When participants described not being involved in decision-making, they explained that this was because they are the most junior doctors and did not have sufficient clinical knowledge about disease or treatment options.

Jonah: "I feel like if you go on a surgical ward round you're completely unqualified to be part of the decision-making process [..] because you can't do the operations." *(FY2, 22 months since graduation)*

One participant, Catriona, also felt that her opinion was not considered by senior doctors but described instances in which she had led the decision-making. Catriona described believing patients were dying but the consultant was not taking responsibility to change the goal of the patient's care.

Catriona: "He wasn't a surgical candidate, they just glossed over him every day. [..] And, he wasn't priority, they knew he wasn't going to get better, so they just kept pumping him full of antibiotics that weren't doing anything [..] That guy who had the small cell lung cancer, I just said, put him onto anticipatory care." *(FY1, 9 months since graduation)*

In this example, Catriona had described giving the patient medication which is typically used for symptomatic relief in dying patients in hospital ("anticipatory care"). Catriona admitted that this was beyond what would normally be expected for her but felt that she was acting in the patient's best interests.

5.2.1.4. Quality of patient care

> Rosie: "If they're going to die, you want it to be the best manner possible." *(FY2, 13 months since graduation)*

Participants indicated that they value patients receiving a good standard of care, and had a desire for the patients to be asymptomatic at the time of death. The healthcare setting was viewed as not routinely set up for providing good end-of-life care, and the care was often inadequate.

> Camille: "There's just this culture of 'you're in hospital to have treatment'." *(FY2, 27 months since graduation)*

The change away from treating with curative intent was associated with providing fewer interventions. Failure to do this was viewed negatively. CPR at the time of death were especially poor care.

> Camille: "I've been involved in resuscitations that, the whole way through, you're thinking, 'why on earth are we doing this'? You know, if it was your relative, it feels like such an intrusion." *(FY2, 27 months since graduation)*

Participants also described hospital departments which provided good quality care for patients approaching the end-of-life. These departments were those where consultants were skilled at recognising patients who were not going to recover and making appropriate decisions.

> Rosie: "Medicine of the Elderly was a really good situation, people planned very well, but surgery was very poor and then medicine was variable." *(FY2, 13 months since graduation)*

Differences between specialties were sometimes rationalised by the relative frequency with which certain patient types are seen in each specialty, and the skills of different specialists. Departments in which patients approaching the end-of-life were commonly cared for, were often seen as those providing the best quality care. However, differences between departments was also seen as a potential strength.

> Eve: "Every team has different viewpoints and that's why it's good to have different teams because you want to have differing opinions, so you can come to a well-balanced decision." *(FY2, 22 months since graduation)*

Generally, the best care was perceived when the patient approaching the end-of-life did not undergo further investigations or 'active treatments'. In contrast, in some

instances, withholding treatments, for patients approaching the end-of-life, was considered to be poor care.

> Victor: "The patient went to ITU, had inotropes, made it through the night, and was home in like three days. You could argue that's worth doing. All these people had just written him off because they were just seeing metastatic pancreatic cancer." *(FY2, 15 months since graduation)*

In this example, Victor believed it was appropriate for a patient with advanced cancer to be admitted to intensive care and undergo invasive treatment. This suggests that care is not always straightforwardly considered good when the decision is made not to proceed with life-prolonging treatments for patients approaching the end-of-life.

5.2.2. Understanding the approach to end-of-life

> Tanya: "You need to look at why they've come into hospital, age, comorbidities, have they already got a DNR. Is this a subsequent admission? Those kinds of things." *(FY2, 14 months since graduation)*

This over-arching theme relates to what causes participants to perceive certain patients to be approaching the end-of-life, and what factors influence perceived appropriateness of altering the goal of the patient's care.

5.2.2.1. The patient

When identifying patients who are approaching the end-of-life, participants described elements related to the patient and their condition. One key factor is age.

> Jonah: "If it's little old Dotty who's 90 something, who doesn't look like she wants resuscitating anyway, it's less of a difficult discussion." *(FY2, 22 months since graduation)*

Patients deemed elderly were easier to identify as approaching the end-of-life. These patients were considered to have led an adequate length of life, therefore could be accepted as 'becoming palliative' more readily than younger patients. Likewise,

patients who were deemed young were those for whom it was more difficult to identify as approaching the end-of-life. Young age was associated with having fewer co-existing conditions and more likely to have an acute illness amenable to treatment.

> Lukas: "If they are young then I feel we should be more active with the treatment because of the potential life lost." *(FY2, 15 months since graduation)*

For younger patients, there may be a longer period of giving treatments with curative intent, and interventions were more invasive. When younger patients died there was greater difficulty accepting this.

> Marta: "...people want to get better and if I was in my 40s and somebody told me you were not going to do CPR, I'd probably be quite upset." *(FY2, 9 months since graduation)*

The very youngest patients – children – were the ones deemed most unusual to die, the most difficult to accept as dying, and those for whom the most interventions should be attempted.

Eve: "It's really sad and difficult because, unlike, say, with an adult who has terminal cancer you feel like they've not even had a relatively normal life, and the children almost always don't really understand probably what is happening." *(FY2, 22 months since graduation)*

For adult patients, there was no exact demarcation between young and elderly. There were also certain patients who fell in-between which would make it more challenging.

Harry: "I think it's very easy for me to have someone who comes in *in extremis*, who's young, who's otherwise fit and healthy, to say, intubate them, do everything. Whereas there's probably a group somewhere in the middle, sort of younger-older patients" *(FY2, 13 months since graduation)*

Participants did not only consider age, but more generally the patient's health and quality of life. Generally, patients with chronic conditions were easier to recognise as approaching the end-of-life, and for whom treatment without the aim of cure may be more appropriate. However, considering how "reversible" a patient's condition is was used when deciding how much invasive treatment to offer.

Rosie: "It depends very much on what they have, so if they've got a chronic condition, that's not going to benefit from them being intubated, [..] but if they have a reversible cause, if they've just got a bad pneumonia and we feel that you can get better on antibiotics, then definitely they can refer for ITU, even if they are older." *(FY2, 13 months since graduation)*

It was important to look at patients as individuals rather than taking a blanket approach. This involved consideration of the patient's quality of life and usual social functioning.

Catriona: "Quantity of life is nice and easy. Quality of life is a much more difficult thing to quantify. Because what is quality of life to somebody? Sitting in front of the TV and reading a newspaper each day, is potentially a great quality of life for one person, but it might not be for another." *(FY1, 9 months since graduation)*

Generally, for patients approaching the end-of-life, quality of the patient's remaining life was deemed to be made poorer by continuing treatments with curative intent.

Camille: “I can think of one patient who I think we all felt that he was nearing the end-of-life and that continued attempts at hospital treatment were unlikely to be successful because it was making him a bit delirious and it was depriving him of a home environment.” *(FY2, 27 months since graduation)*

Familiarity and relationship with the patient aided the doctor in understanding the patient’s condition, medical history, what they would consider to be good quality of life, and if the patient was approaching the end-of-life. Similarly, encountering patients who the doctor had never met before made decision-making difficult.

5.2.2.2. Implications of treatment

Perceived implications of treatments also influenced understandings of patients approaching the end-of-life. This included the effect that it would have on the patient (e.g. being unpleasant, a burden, reducing quality of life) and the outcome for the condition.

Tanya: "Do you treat them just supportively on the ward? If they suddenly deteriorate do you go down the route of quite harsh treatment, IV antibiotics? Do you send them to ITU for invasive monitoring and fluids?" *(FY2, 14 months since graduation)*

Continuing certain treatments may be invasive, aggressive, or unfair. Treatment decisions were considered as a spectrum, with less invasive treatments – oral medication, or care on the level of a normal level ward, non-surgical treatment – being more readily provided than invasive treatments – intubation, or care in intensive care unit, surgery. Within this spectrum, decisions about the extent of invasiveness were conveyed.

Charles: "Where you draw the line, what the highest level of treatment's going to be; it might be decided that you will have oral antibiotics for an infection but wouldn't step up to intravenous antibiotics." *(FY2, 21 months since graduation)*

Although care with curative or life-prolonging intent may still be taking place, limits may be decided about invasiveness of care which would be offered. It was important to consider if CPR should be offered because it was invasive, undignified and unpleasant if the patient was dying.

Catriona: “Obviously, everybody rushed in, we didn’t have a proper DNACPR [..] it’s quite demoralising, you run in there thinking you could potentially save a life. Then, you get there and think, ‘this is inappropriate, she’s very elderly, now completely losing all of her dignity’.” *(FY1, 9 months since graduation)*

From this viewpoint, patients who suffer cardiac arrest, but for whom CPR is inappropriate, may be considered as dying. What constitutes appropriate treatment is not always clear. This affected the work of foundation doctors, when they are unsure of the level of treatment which should be provided.

Jonah: “Some people are obviously not going to critical care, but there's clearly a massive grey area.” *(FY2, 22 months since graduation)*

Marta: “It’s always quite difficult to know when you’re on call.” *(FY1, 9 months since graduation)*

A further difficulty is knowing in advance if treatment is going to have the intended outcome. It may be most appropriate to try treatments for a period, and then review the results.

Harry: "We will give them *x* number of days of antibiotics and at that point we will reassess." *(FY2, 13 months since graduation)*

Decision-making differed between departments, specialties and/or individual consultants. Eve described an incident where she had been instructed by her consultant to refer a patient to an on-call anaesthetist for insertion of a central venous line. The anaesthetist considered this inappropriate.

Eve: "They said, 'this is ridiculous, why on earth would you put a line in someone who has no quality of life'. So, you're kind of the middle person, like, 'I'm just doing my job, but I kind of agree with you, I can see where you're coming from'." *(FY2, 22 months since graduation)*

This highlights the contrast in views of levels of treatment between professionals. The experience of being caught between different views was common among participants.

Scarlet: "It puts you in a really difficult situation [..] we had an anaesthetist come down to assess whether he'd be fit for anaesthetic. And the anaesthetist said, 'why am I here, what are you doing'?" *(FY2, 14 months since graduation)*

Decisions were ultimately made by consultants, and the foundation doctor was responsible for acting on these decisions. Consultants sometimes found it difficult to limit invasiveness of treatment or alter the goals of care.

> Camille: "I suppose the act of stopping treatments always feels very final and definitive [..] you don't stop things until you're quite confident that somebody's not going to survive and they're being distressed by the treatments." *(FY2, 27 months since graduation)*

Deciding not to continue treatments with life-prolonging potential was difficult. It was acknowledged that the ultimate decision lies with the consultant and was not straightforward.

5.2.2.3. Imagining self

Participants also conveyed the approach to the end-of-life with reference to imagining themselves in the position of another. This included when the participant imagining her/himself as the patient.

Catriona: “For me, it’s like, would I really want to linger around for another week with tubes in me? [..] Do you really want that? And, we’re providing him with a completely undignified death, doing bloods constantly.” *(FY1, 9 months since graduation)*

Participants also described imagining the patient was a member of their family.

Harry: “I think if it was me or one of my family lying in that bed I don’t think having a [venous cannula] jabbed into me would be what I would want in the last few hours of life.” *(FY2, 13 months since graduation)*

Camille: “Both the idea of a *Do Not Resuscitate* order for my parents and of CPR on my parents are appalling.” *(FY2, 27 months since graduation)*

Similarly, participants also imagined themselves being the consultant. Participants tended to see themselves as enactors of decisions made by consultants, but illustrated their feelings about patient care by imagining themselves as the decision maker.

Zach: "I felt that if I was that consultant in the future, it would have been my judgement that this patient should not be for resuscitation." *(FY1, 9 months since graduation)*

However, participants tempered these views of what they would do in the consultant's position, by acknowledging that being the one to have to make these decisions was difficult.

Catriona: "It's so easy to judge with hindsight, isn't it, saying, you should have stopped five days ago, but five days prior it would have been not so easy to say that." *(FY1, 9 months since graduation)*

This is congruous with the perception that foundation doctors are the most junior, and it is not up to them to make the clinical decision that certain treatments should cease.

5.2.3. Role of the doctor

> Victor: "I mean obviously you have your own ideas. But you're not making those calls at FY2 level." *(FY2, 15 months since graduation)*

This section will consider the perceived roles played by doctors in the care of the patient approaching the end-of-life.

5.2.3.1. Being junior

> Rosie: "…as a junior doctor you're often not necessarily listened to very well by your seniors, and often they say, 'we're going to do it this way', and often we just accept that." *(FY2, 13 months since graduation)*

The participants were newly graduated doctors, and the terms 'junior doctor' or simply 'a junior' were used by all participants to refer to themselves and their peers. Being junior was more than simply a nominal title, but denoted a doctor who was recognised as lacking in knowledge and experience, who carried out menial tasks, and did not have the authority to make decisions.

Tanya: “I would look at a senior member of staff for making that decision, because you would feel more comfortable trusting their opinion than someone that's just been out of medical school for two years.” *(FY2, 14 months since graduation)*

It would not be expected for junior doctors to make decisions, but part of being junior was learn about these decisions.

Zach: “I think the tricky part of being a junior doctor is to understand the thought process behind decisions regarding further treatment, and ceilings of escalation, and things.” *(FY1, 9 months since graduation)*

Frustration was experienced when foundation doctors disagreed with clinical decisions made by more senior doctors.

Catriona: “I came along thinking, we’re prolonging life and it’s quite frustrating. But then, again, I’m a junior, so it’s difficult for me to know, in terms of experience, rather than somebody who is 15 years down the line, who has seen everything.” *(FY1, 9 months since graduation)*

Being junior was also a reason for not engaging with certain lines of discussion with patients and their relatives.

> Scarlet: "If I can't sign the [DNACPR] form, I probably shouldn't have that discussion [..] if it did end up coming back that the patient had another discussion, or hadn't meant what had been interpreted, then that just causes more difficulties." *(FY2, 14 months since graduation)*

Furthermore, participants perceived that other team members viewed them as 'being junior'.

> Victor: "If I made that decision people will be like, 'well, you're not qualified to make that decision'. So regardless of what you think about it, people aren't going to take that seriously, whether I'm right or wrong." *(FY2, 15 months since graduation)*

Although generally the term junior doctor denoted a training grade doctor, the limits of being a junior were not clearly defined. For example, being junior was associated with lack of knowledge and competence, and when participants reflected on having increased in competence, they saw themselves as 'less junior'.

Rosie: “If I was to go back to Medicine of the Elderly, maybe I’d feel more confident because I’ve already done it, whereas if I was to go to Gynaecology, even if I was to go in two years’ time, I’d probably still be like, ‘I’ve no idea, I’m a junior doctor, someone help me’.” (FY2, 13 *months since graduation)*

Participants conveyed the importance of experience for knowing the correct course of action in certain circumstances and to being able to make decisions.

Tanya: “You’ll probably always be junior to someone. But I think before you've really started in that speciality training and you've got a decent length of time in one specialty, it would be hard to say you're senior [..] it's all about seeing stuff a certain amount of times and working out what to do.” *(FY2, 14 months since graduation)*

Participants described working alongside more experienced junior doctors (also not yet fully trained), but who were senior compared to them.

Catriona: “I did tell the [registrar] and he was like, ‘yes, this seems inappropriate’ but the hierarchy meant that he couldn’t step in.” *(FY1, 9 months since graduation)*

In this example, Catriona described raising concerns to a more senior doctor that a patient was approaching the end-of-life. Although the doctor she spoke with was more 'senior' to Catriona, she felt he was still unable to alter the decisions for the patient as he was more junior that the consultant. Being junior could also lead to feelings of vulnerability.

> Theo: "They were just very persistent to wait to hear the same conversation that they'd heard from the consultant that morning [..] they felt more comfortable to snap back at me and complain about the fact that there was nothing more that could be done." *(FY2, 14 months since graduation)*

Theo described his perception that he was being singled out after the consultant had explained curative treatment was no longer going to be offered. Although participants openly identify as junior, this is at times was experienced negatively. Not being the one who makes decisions does not mean that the FY is immune from negative effects of decision-making.

5.2.3.2. Role of the foundation doctor

As foundation doctors, participants perceived their role as generally to carry out perfunctory tasks.

> Victor: "I was reminded *a number of times* that my job was to write discharge letters." *(FY2, 15 months since graduation)*

Foundation doctors provided care for patients who had already been identified as approaching the end-of-life. This included providing symptomatic relief.

> Jonah: "It's a core function of what we do, particularly as the junior end of junior tier medicine, is like quick, *ad hoc* palliative care." *(FY2, 22 months since graduation)*

Foundation doctors also assessed sick patients, but they would do so under the general supervision of more senior doctors.

Tanya: “I think as a junior doctor you've got to assess the situation, and if you feel at any point that you're struggling or you're not comfortable with what's going on you need to ring your registrar.” *(FY2, 14 months since graduation)*

Foundation doctors played an important role in identifying when patients were deteriorating. This involved alerting more senior doctors and checking for agreement with any clinical decisions.

Catriona: “You’re at the bottom of the pile but you’re there to catch the deteriorating patient [..] and you’re the person that has to stabilise them and get help.” *(FY1, 9 months since graduation)*

Participants described experiences of reviewing sick and deteriorating patients who transpired to be approaching the end-of-life. Because it is not within their scope of responsibility, the foundation doctor may not necessarily consider decisions related to patients approaching the end-of-life.

Marta: “Had the nurses not said anything to me, I probably wouldn’t have thought he was about to die.” *(FY1, 9 months since graduation)*

At times, foundation doctors had not considered patients were approaching the end-of-life, therefore did not communicate this possibility with their seniors.

Theo: “I also might have been guilty of not conveying the seriousness of his deterioration, largely because I didn't really appreciate how serious the deterioration was.” *(FY2, 14 months since graduation)*

Responsibilities varied somewhat between settings. In certain places, foundation doctors were given less responsibility, and more clinical decisions were likely to be made by the consultants.

Eve: “Paediatric haem/oncology is clearly very specialist, so everything is consultant-led, and even registrars have to be very senior, say, to prescribe chemotherapy. So, we’re more observers.” *(FY2, 22 months since graduation)*

In other settings, participants felt they had more responsibility. In these experiences, participants conveyed that it was not fair on junior to be put in this position. When put into a position where acting beyond this scope, participants felt unease and a sense of injustice.

> Catriona: "It's not fair on a junior, a junior cannot have that discussion with somebody, unless it's been discussed by a consultant." *(FY1, 9 months since graduation)*

Catriona went on to describe an example where she was unable to contact the consultant to institute and discuss a DNACPR order.

> Catriona: "I couldn't get hold of the consultant, he wasn't interested, he just basically would hang up on me, and that would be the end of that, in terms of DNACPR." *(FY1, 9 months since graduation)*

In other examples, participants expressed that in some settings, even if decisions were made by senior doctors, the responsibility for communicating was the left to the foundation doctor.

Theo: "Often the treatment ladder comes to an end and then it's down to the F1 to try and communicate the fact that there's nothing more that can be done for the patient to the family member even though it's commonly held between all of the team members." *(FY2, 14 months since graduation)*

In these ways, foundation doctors experienced negative effects of being positioned as junior within a hierarchy.

5.2.3.3. Tensions in the role

In practicing the role of the foundation doctor, participants described experiencing tensions. Difficulties were perceived when foundation doctors feel that adequate decisions were not made by a consultant.

Marta: "Whether it was necessary to start the antibiotics, probably not, but having not had a senior telling me what to do, just felt I better start antibiotics just in case they make a difference to his symptoms." *(FY1, 9 months since graduation)*

Lack of senior decision-making caused uncertainty and dissatisfaction for participants. Furthermore, when decisions have been made the foundation doctor may disagree with them.

> Scarlet: "They would not accept that this man was dying, that he had multi organ failure […] he was getting really distressed with NG tubes, and fluids, and there was no cause for it." *(FY2, 14 months since graduation)*

In this example. Scarlet described a treatment decision as not in the patient's best interests. Conversely, Victor described an example where he felt the decision not to provide treatment with curative intent was inappropriate.

> Victor: "He didn't have that many comorbidities, was completely functioning independent [..] my mind was like well, if the consultant really feels that strongly about it then she can discuss it and explain it because I can't rationalise it." *(FY2, 15 months since graduation)*

One reason proffered why consultants may come to poor decisions, or avoid decision-making, was that consultants may not be well informed about the patient. Foundation doctors spend more time with patients than consultants.

Rosie: “Ward rounds are very quick and it’s all about blood results and what we’re doing and can we get them home, and actually there’s not very much kind of feeling of like, how are they doing, personally.” *(FY2, 13 months since graduation)*

There were rare instances where foundation doctors had gone against the normal hierarchy by making decisions normally made by senior doctors.

Rosie: “When the patient initially came back to the ward and was really unwell, one of my colleagues prescribed them ‘anticipatory care’ medications, and then the consultant came along and was like, ‘this woman isn’t dying’, [..] he was like, ‘why have you gone down the palliative care route?’, and then she died within five days and it was like, ‘well, that’s why, because we could see that she was really unwell’.” *(FY2, 13 months since graduation)*

At other times, by lack of decisions meant that the foundation doctor may feel compelled to put pressure on the consultant.

Catriona: “It took me two days to get the consultant, of me calling, and just annoying them, and they got really annoyed at me, and they just weren't interested at all.” *(FY1, 9 months since graduation)*

In contrast, one participant, Harry denied any difficulties with consultants’ decision making.

Harry: “I think most consultants are pretty good at saying, ‘actually no, if that happens don’t do this, don’t do that’.” *(FY2, 13 months since graduation)*

Harry described undertaking an audit of patients’ clinical notes, reviewing whether adequate plans were made in anticipation of potential deterioration.

Harry: “For the first couple of days we had to be quite vocal in saying, ‘what's your escalation plan for this?’ It was very interesting because they changed their practice. All of a sudden, every day they would document it, about escalation plans.” *(FY2, 13 months since graduation)*

Although Harry's perception was positive, there was generally unease among participants about voicing concerns about patients approaching the end-of-life. In some instances, participants felt that it was not their place to voice these.

> Catriona: "The idea of speaking to somebody more senior about it, is probably not quite as pleasant." *(FY1, 9 months since graduation)*

Whether the FY was able to convey their concerns to the consultant varied depending on the consultant.

> Lukas: "Some of them were nicer than the others in responding to questions in general." *(FY2, 15 months since graduation)*

> Charles: "I suggested to the consultant that she probably shouldn't be for active resuscitation […] the consultant kind of came round to that idea but it just took a little bit longer" *(FY2, 21 months since graduation)*

Participants reported their ability to voice one's concerns increased over time.

Camille: “I feel much more confident by the end of F2, and I think that’s a lot to do with realising that when I feel uncomfortable about the care, it needed discussion with someone more senior.” *(FY2, 27 months since graduation)*

While working out of hours, foundation doctors were often called to review patients when the consultant was not physically in the hospital. At these times they may feel unable to call the consultant at home.

Harry: “I think realistically the only way you would ever get around that is to phone the consultant who is looking after that patient, which, of course, as an FY1 to phone a consultant at three o'clock in the morning is pretty bold.” *(FY2, 13 months since graduation)*

Although raising questions about patients approaching the end-of-life may be done by a foundation doctor, this may be limited by the time of day.

5.2.4. Preparation for the role

This section will present themes related to how participants perceived medical school had prepared them for fulfilling the role of the foundation doctor caring for patients approaching the end-of-life.

5.2.4.1. Adequate preparation

Few data related to concepts of adequate preparation. Victor was the only participant who felt that his undergraduate preparation for this area of practice had been fully adequate.

> Victor: "I just saw a fair few situations where they were just withdrawing care slowly, in various attachments, it was more obvious fourth and fifth year." *(FY2, 15 months since graduation)*

Victor recounted having seen patients approaching the end-of-life in the clinical setting. This had allowed him to consider the importance of this area of care for practice.

Scarlet: "We had a really nice consultant […] he said that it's the good physicians that can recognise when patients need to be left alone, need to have dignity. Rather than the ones that keep tapping away to try and get there, to try and get something." *(FY2, 14 months since graduation)*

Although Scarlet's perceptions of her experience of her undergraduate preparation had not been as wholly adequate as Victor's, Scarlet recounted having considered the need to rationalise investigations as a medical student thanks to an individual teacher.

5.2.4.2. Inadequate preparation

Participants mainly perceived inadequate preparation. In some cases, although participants may have been aware of these situations, they did not fully understand the approach to the end-of-life or appropriate treatment decisions.

Cassie: "I, kind of, understood it that people had comorbidities and they might not be able to have [CPR], but I didn't fully understand about the decision making behind it and who made the decision." *(FY2, 22 months since graduation)*

As students, participants were not necessarily aware that care of patients approaching the end-of-life would fall under the responsibilities of the foundation doctor. In fact, it was surprising to learn that foundation doctors were responsible for caring for dying patients in the acute general hospital setting.

> Camille: "I don't think it had ever occurred to me that, as a mere FY1 surrounded by more senior doctors, I would be responsible for someone who was dying." *(FY2, 27 months since graduation)*

Providing care for patients at the end-of-life was experienced when students, associated with certain settings, e.g. specialist palliative care. It was not necessarily clearly associated with other more general healthcare settings.

> Jonah: "I think we miss out on the basics of good palliative care by only looking at the very, very complex, high end, brilliantly done, [specialist hospice unit] … But you miss out what can I do as an F1 for people who are just dying on the ward" *(FY2, 22 months since graduation)*

Marta: “Not the patients who were acutely ill not getting better. It was mostly patients who are expected to die dying.” *(FY1, 9 months since graduation)*

As medical students, participants had been exposed to patients who were expected to die. Generally, they did not have preparation for patients with illness at the point of approaching the end-of-life, or realise how these experiences related to their work in more generalist settings. These understandings were developed after beginning practice.

5.2.5. Influences on workplace learning

This section will present themes about perceived influences on learning about patients approaching the end-of-life and experienced through work, after graduation and beginning practice.

5.2.5.1. Nurses

> Tanya: "We chat to the nurses, they know them. They will have been with the patient for the whole day or the whole night. They've got eyes on patients that you can't have." *(FY2, 14 months since graduation)*

All participants described interactions with nursing staff at times when patients were approaching the end-of-life. Nurses played an important role in the care of patients approaching the end-of-life, and the familiarity that they had with the patients was a contributing factor to this.

> Jonah: "Certainly the nursing staff will notice deteriorations that we don't. People maintain their blood pressures and their resp. rates for a lot longer than they maintain their willingness to chat and their appetite." *(FY2, 22 months since graduation)*

Nurses spent more time in the presence of patients than doctors, and this allowed them to identify when patients were deteriorating which may not be evident to a doctor.

> Camille: "Nurses are much, *much* better at judging whether or not someone is dying than your average junior doctor [..] even junior nurses have spent more hours and more nightshifts on wards than the first couple of years of medicine and, some of them have decades of experience on you, and will know the patients generally quite well." *(FY2, 27 months since graduation)*

This experience of having seen similar situations before meant nurses made their own assessments of patients approaching the end-of-life, which could be helpful. Nurses were aware of this, and that they played an important role in guiding junior doctors.

> Camille: "It's probably one of the situations where they're most likely to speak up, actually." *(FY2, 27 months since graduation)*

Jonah: "They would sit down and go 'he's dying', and you would go 'yeah, I maybe hadn't thought of that'." *(FY2, 22 months since graduation)*

Nurses often asked foundation doctors to re-evaluate the intention of treatment, prompting the doctor to consider if the patient was dying. Often this was appreciated by participants.

Catriona: "Nurses are very involved, and they know the patients much better than I do, because obviously I've come on at night. And they've been looking after them 24/7. And their opinion is extremely valuable." *(FY1, 9 months since graduation)*

However, there were times when nursing input was could make the work of the doctor more challenging. Participants were mindful of the differences between nurses and doctors. Doctors were stronger in knowledge of disease. This was perceived particularly in cases where the patients had an uncommon condition.

Catriona: “I don’t know how to say this diplomatically, but nurses aren’t medically trained, and you do have to acknowledge that their opinions are important, but they may not be aware of all medical scenarios. [..] So, if they say, ‘why are you doing this’? You can say, well, it’s because of this or that’.” *(FY1, 9 months since graduation)*

Participants expressed frustration at times when they felt input from the nurses did not account for all important factors. Their input was perceived at times as attempting to put pressure on the doctor to act in a certain way.

Lukas: “Sometimes they ask for it based on purely on how patients look at the given moment, but they don’t always take into account what their baseline is and sort of how reversible the problem is.” *(FY2, 15 months since graduation)*

This presents a notion that nurses will sometimes not accept a decision from the doctors which does not conform with their assessment.

Rosie: "There was one patient who she kept saying every day, and I was like, 'no, we're not doing that'." *(FY2, 13 months since graduation)*

Theo: "She did not appreciate the level of investigation I was doing for this patient [..] I felt that she was just trying to pick holes in what I was doing." *(FY2, 14 months since graduation)*

The lack of acceptance by nurses of medical decisions with which they disagreed was perceived, at times, as undermining.

5.2.5.2. Organisation

Workload and organisation of the workplace affected the learning of participants in their care of patients approaching the end-of-life. A distinction was made by participants between being part of the usual 'day team' which looks after the patient during normal 'day' hours and being 'on-call' during the out-of-hours (OOH) period – evenings, nights and weekends.

Catriona: “If they deteriorate during the day, you have more people there, the consultant is available, so it’s fine. It’s on call, when there’s skeleton crew, you don’t know the patient, the consultant is asleep, Med [registrar] is dealing with some accident in the ER department, and you don’t know what to do because the conversation has not been had.” *(FY1, 9 months since graduation)*

If patients deteriorate during daytime working hours, it is easier for the foundation doctor to seek advice and be facilitated in providing appropriate care for the patient. However, foundation doctors often work outside these hours, including being called to review patients who are deteriorating, who they have not previously met, when more senior doctors are not immediately available.

Tanya: “If colorectal patients didn't have a plan in place you would know those patients because you'd seen them during the day. Whereas the urology patients, you'd literally never seen them, and they could get sick quickly.” *(FY2, 14 months since graduation)*

When the patient was not known then it was more difficult to discern the correct course of action. Being in this position could make the foundation doctor feel vulnerable, particularly when the patient’s condition was deteriorating.

Camille: “It all felt quite unreasonable, you didn’t have any sense of what the aim was for the patient. Obviously, that depends a bit on someone’s ward round notes before you.” *(FY2, 27 months since graduation)*

The doctors normally looking after the patient during daytime hours may have already considered if the patient was approaching the end-of-life, but the foundation doctor would not necessarily know this. Foundation doctors were not ultimately responsible for decision making, and if unsure of the correct course of action, would need to seek a more senior doctor. This was more difficult while working OOH.

Catriona: “Quite often I have spoken to the medical registrar, who is on call for huge swathes of the hospital, and quite often they’ll say, actually I don’t want to be the one to make that decision” *(FY1, 9 months since graduation)*

Zach: “During night shifts you're looking after patients who are very unwell. And the medical registrar is obviously very busy as well, looking after patients in HDU and ITU.” *(FY1, 9 months since graduation)*

Although more senior doctors are available (registrars), it can still be difficult for foundation doctors to access a senior doctor who is able or willing to make decisions

about patient care. Lack of continuity of doctors caring for the patient was also challenging.

> Harry: "You get six or seven members of the family all wanting to ask their own questions and you're sort of left fielding these questions and quite often I suppose I've walked out of that situation thinking, 'why on earth has their normal team not had that conversation with them'?" *(FY2, 13 months since graduation)*

One means of overcoming disparities in working during the day and OOH was documentation in patients notes.

> Catriona: "Somebody's got a crashing blood pressure or something like that. So you think, 'oh, quickly give fluids'. And then you think, 'oh, six pages back they said, if she deteriorates, this is the plan'. And it's just because it's a few pages back, you may have missed it and then you've gone and started fluids which is not what they want." *(FY1, 9 months since graduation)*

Having clear documentation was necessary to understand the decisions of previous doctors. It was easier to understand and provide care for patients approaching the end-of-life if it was clear from the notes that this was anticipated. When that documentation is not present it can contribute to frustration and confusion.

Marta: “Nothing had been done about it and because he’d been worsening over the weekend, I thought, ‘is this a conscious decision the team have made, but just not documented? That he would be for purely palliative treatment’. There was nothing to say in the notes.” *(FY1, 9 months since graduation)*

The patient notes acted as a mode of communication between the ‘day’ and OOH teams.

Camille: “You would write the notes as much as you could, ‘this treatment direction isn't working, should we be looking for an alternative?’, and sort of hope that this would be picked up the next day and you would see a ward round entry the next day that would just sort of say, ‘continues to have dreadful cellulitis, continue IV treatment’.” *(FY2, 27 months since graduation)*

A further means of communication between shifts was handover meetings, when pertinent clinical information was communicated between doctors at the point of shift changes.

Tanya: “You need to work it out before handovers, especially going onto nights, if you've got a sick patient, you'd see them being handed over, ‘what's the ceiling of care? Is there a DNAR? Because if this patient suddenly goes acutely unwell in the middle of the night, we're not their usual team, what do we need to do’?” *(FY2, 14 months since graduation)*

Having a handover – where it was usual for questions to be asked about what level of treatment might be appropriate for each patient – acted as a prompt for participants to make sure such decisions were made. With this handover information in place, participants described being able to discern which treatments were appropriate when working OOH.

5.2.5.3. Time and experience

Participants perceived that passage of time had influenced their learning and practice. Looking back at their early experiences, they felt that there were many things they needed to learn.

Camille: “It was my first job so it's hard to put it in context now because it was, amongst other things, very, very stressful and sometimes you felt like you were being bombarded with information.” *(FY2, 27 months since graduation)*

As time had passed, participants became more comfortable in their roles. Over time, they increased understanding of the significance of the approach to the end-of-life.

Lukas: “I would feel more comfortable asking people, ‘what’s the long-term plan and did we have those discussions’? I would probably not feel I would know what the answers should be, but I would probably feel more confident raising it.” *(FY2, 15 months since graduation)*

Engaging in discussions with consultants contributed to this learning.

Catriona: “The more you get involved in discussions, the better you get at recognising that, and having an opinion [..] I suppose I’m starting to get enough to look at somebody and think, ‘they look like they’re dying, don’t they’?” *(FY1, 9 months since graduation)*

Increasing experience over time allowed the doctor to be able to recognise similar situations, and increased confidence in one's own abilities.

> Tanya: "I think you've just really got to go with where you feel comfortable, and that might change for each patient if you've seen and managed something similar before than if it's brand new." *(FY2, 14 months since graduation)*

> Rosie: "The consultant said to me, 'well, why has that decision been made?' [..] I didn't say, 'you weren't here', which I would probably say now." *(FY2, 13 months since graduation)*

Increased confidence also allowed some participants to feel they were more likely to stand up for their viewpoint to the consultant.

5.2.5.4. Emotional reactions

Participants had emotional reactions to patients approaching the end-of-life. Generally, participants agreed that it was always at least slightly sad when a patient under their care was dying or had died. At times, this was viewed as simply unfortunate but an inevitable part of the job of a doctor.

Scarlet: “I think you're probably in the wrong job if it doesn't affect you.” *(FY2, 14 months since graduation)*

However, there were factors which made certain cases more difficult to cope with emotionally for the participant. It was worse if s/he knew the patient well prior to their death.

Harry: “When you lose a patient you’ve got to know a bit better it can knock you off a bit and it can be a bit more difficult.” *(FY2, 13 months since graduation)*

Deaths of children were more challenging emotionally than those of older patients.

Eve: “I guess with an adult you feel that they understand their situation so that maybe they can somehow understand what’s going on, whereas with a child it’s very difficult for them to understand.” *(FY2, 22 months since graduation)*

Deaths which occurred without prior acknowledgement that the patient was dying, or when that acknowledgement occurred very close to the end-of-life, were particularly difficult for participants emotionally

Catriona: "It turned out the patient had decided he no longer wanted treatment, and then subsequently died the next day. […] I got more upset by the fact that it was him that had to make the decision to withdraw treatment and that we were just blindly treating the guy and sticking tubes in everywhere." *(FY1, 9 months since graduation)*

Participants perceived there was poor quality care when investigations and/or treatments with life prolonging intent continued for patients approaching the end-of-life. Perceived poor care was upsetting.

Victor: "That was quite an upsetting case because the thought of that, if you actually think about it, actually being in the [Magnetic Resonance Imaging] scanner and you arrest, it's probably quite a horrible thing to happen." *(FY2, 15 months since graduation)*

It was particularly upsetting for participants to perform CPR.

Camille: “You lose that human connection if they die in a [resuscitation] attempt surrounded by bodies and needles and all the paraphernalia. You know, it becomes a traumatic death and you feel like you’ve contributed to it, really.” *(FY2, 27 months since graduation)*

Despite emotional reactions, controlling one’s emotions was generally seen as good practice.

Tanya: “It’s about controlling yourself in front of them and the family.” *(FY2, 14 months since graduation)*

Generally, participants felt displaying emotions at work was not what was expected of a doctor. However, one participant felt that it could be good for the patient’s relatives to see that they were emotionally affected by the death of the patient.

Harry: “Although I've found quite often families appreciate seeing that actually the medical team aren't sort of carrying on nice and jolly with the rest of their day and actually sometimes that can help in their grieving process.” *(FY2, 13 months since graduation)*

Participants described coping strategies they used in order to control their emotional reactions. This include discussion and debrief within the medical team.

Camille: “When you do have deaths, accept people’s offers of discussing it afterwards.” *(FY2, 27 months since graduation)*

Discussion within the medical team was helpful to increase understanding or assure oneself of correct understanding. This gave participants the opportunity to reflect on the events that occurred and ask questions.

Theo: “I think the focus was on the medical, was to make sure that I didn't doubt my clinical acumen in the case, and we didn't really address the emotional component.” *(FY2, 14 months since graduation)*

Harry: “Most consultants I've worked with who, after a patient has passed away, will come along and say, ‘do you understand everything that happened there?’, I guess more from an educational view more than anything else” *(FY2, 13 months since graduation)*

Although such discussions may be helpful for allaying negative emotional reactions, the focus of such discussions was on factual details. Emotional reactions were not discussed amongst doctors. Likewise, lacking the opportunity to have a debrief with colleagues could lead to ongoing upset and dissatisfaction.

Catriona: “I still do wish I'd discussed it with my registrar. You know, had he seen that all along, or was there a change at some point along the way from an acute exacerbation to a terminal event?” *(FY1, 9 months since graduation)*

Participants described wishing to know that there were no actions which could have been taken to prevent the outcome. Knowing this, and not blaming oneself, was important for coping with situations where patients died.

Zach: “I think what gets you through is the knowledge that you have done everything correctly, and it's not, for example, your negligence, that's harmed the patient.” *(FY1, 9 months since graduation)*

Not feeling solely responsible for outcomes was also helpful for coping with emotional reactions.

5.3. Discussion

This chapter provides a vital next step in advancing this thesis, by considering the learning of the foundation doctor caring for patients approaching the end-of-life and workplace influences on this learning. Here I will discuss the themes in detail, elaborating on how they contribute to and/or contrast with existing literature, and make clear what my findings contribute. I will argue that my findings support the argument that the approach to the end-of-life is learned about through practice as a doctor, having not been understood or developed at an undergraduate level. I will explain the potential wider implications of the findings, and then discuss the limitations of this study. Lastly, I will delineate how these findings advance the overall aims of this thesis.

5.3.1. Considering the approach to end-of-life

For the patient to be approaching the end-of-life went against the norm of the system and occurred through the intention or decisions of doctors. Understandings of what constituted this change were varied. The change may have happened to the patient and/or the care. Participants often used inexact terms to succinctly convey their general meaning (“becoming palliative”, or “for TLC”). Such difficulties in agreeing upon unified meanings in end-of-life care are well documented (Hanratty et al., 2006; Levack, 2014), and have been discussed in Chapter 3. There was variability in how these decisions were made, and disparities between consultants and between departments were perceived. Overall, participants’ views of what makes good care

for patients approaching the end-of-life has commonalities with most descriptions of palliative care, e.g. a focus on symptomatic relief rather than curing or healing (Kilbertus, et al., 2017). In the approach to the end-of-life, there was a disparity between standard care – aimed at prolonging life, potentially more invasive or unpleasant – and care appropriate for the patient approaching the end-of-life. These findings from my UK-based study align with a study of postgraduate trainees in Canada, that found palliative care is perceived as contrasting with standard care (Kilbertus, et al., 2017). This is noteworthy in the context of the UK, where medical literature asserts that end-of-life care is the business of all healthcare professionals and in hospitals (Gomes, et al., 2008; Oliver, 2016).

When a patient was treated as approaching the end-of-life, certain aspects of care were non-standard. This included decisions not to deliver certain treatments, particularly those deemed to be unpleasant and/or unlikely to be effective. However, discerning which treatments were appropriate was difficult. This agrees with existing concepts that discerning if, when, or to what degree end-of-life care may be appropriate is challenging due to uncertainty (Coombs, et al., 2012; Etkind and Koffman, 2016) and demonstrates that foundation doctors are learning about this uncertainty in practice.

Nevertheless, participants were critical of and frustrated when they felt patients were not receiving appropriate care for the approach to end-of-life. The findings reflect that junior doctors share in prevalent concerns of inadequate end-of-life care for patients in hospital (Mason et al., 2013). Their understandings of when a patient was approaching the end-of-life – and care should be changed accordingly – were informed by various factors. These included patient-related factors such as patient age, the chronicity or multiplicity of their diseases, the likelihood of their disease being

reversed and the patient's social functioning. Treatment related factors were also considered including the likely benefit, patient dignity and how invasive the treatment was. In common with previous findings, treatments which may be considered futile in one time or place may not be in another (Gallagher et al., 2015). Participants described being influenced by pre-existing knowledge of the patient, and experiencing difficulty when the patient was new to them. The findings indicate the approach to the end-of-life is not considered by foundation doctors as a discrete, measurable entity, but in reference to their assessment, opinions of the patient, and their treatment options. These factors were considered in qualitative and non-precise ways which contributed to an overall impression of whether the patient was approaching the end-of-life.

Furthermore, findings also reveal that foundation doctors are influenced by empathy. Numerous definitions of empathy have been postulated, but generally empathy is seen as the ability to understand how someone else feels or thinks (Marcus, 1999; Spencer, 2004; Burke et al., 2015). Authors have argued that empathy is crucial to success of healthcare endeavours (Hooker, 2015) and medical practice (Marcus, 1999). It has previously been argued that registrar doctors are influenced in their end-of-life decision-making by empathy (Charman and Esterhuizen, 2016). My findings indicate that foundation doctors are influenced by empathy when considering whether the patient was approaching the end-of-life, through imagining how they would feel in the position of the patient or their relative. This also allowed them to assess whether certain decisions would be in the patient's best interest. They also imagined themselves in the position of the consultant doctor, and understood the approach to the end-of-life by imagining decisions they would make if they were the consultant.

In summary, the findings indicate that in understanding the approach to the end-of-life, foundation doctors are not only influenced by biomedical factors. Understandings are developed through experience of practice and involve perceptions of the patient's social functioning, views on medical treatments, and empathy. These are connected to their knowledge and experience of the patient and their care, and more difficult when the patient and their care are not known to the doctor. Acknowledging and altering treatment plans accordingly for the approach to the end-of-life was a change deemed to occur through decision-making, as discussed below.

5.3.2. Decision-making

The change to the approach to the end-of-life was described as occurring through a decision and/or deliberate change in the goals of care. It was important to participants that patients received good quality care, and what constituted quality for patients approaching the end-of-life differed from general care. These foundation doctors, like other healthcare professionals, have concerns about delays in recognising dying in hospital (Reid et al., 2015). My findings indicate that care was perceived as poor by the FY doctors, for example, when the patient is not acknowledged as 'becoming palliative' prior to their death, when communication is not made adequately with the patient and their relatives, and, especially, when the patient receives attempted CPR.

Foundation doctors are variably included in this decision-making and, despite not having ultimate responsibility, participants conveyed dissatisfaction, frustration or

confusion at times when they felt the correct decisions were not being made. Furthermore, participants may feel uncomfortable if they must carry out actions with which they disagree, or when they are caught between consultants who have different opinions about appropriate care. They may feel uncomfortable when asked to act against what they believe to be in patient best interest. However, it was acknowledged that these decisions (and, as above, discerning which treatments are appropriate to consider) were not straightforward. Although in a minority of cases there might be a clearly correct course of action, uncertainty resulted in 'grey cases' in which there was no clearly correct course of action. Participants also acknowledged that although they criticised the decision-making made by consultants, these decisions must be difficult.

Previously documented reasons why treatments for patients at the end-of-life may be continued include doctors being trained to treat, uncertainty, patient wishes, professional incentives, and a perception that dying patients do not belong in a hospital ward (Chan et al., 2017; Lightbody et al., 2018). In the present study, participants described certain departments not being pro-active or willing to consider treatment changes for patients approaching the end-of-life. This aligns with previous findings that different specialities vary in their attitude towards recognising dying (Redman et al., 2017) and offer differing levels of support to junior doctors in end-of-life care (Price and Schofield, 2015). Furthermore, my findings indicate that foundation doctors are concerned by patients approaching the end-of-life who are not treated accordingly. Although non-beneficiary interventions have been described (Lightbody et al., 2018), participants perceived that continuing treatment with curative intent was not only non-beneficiary but detrimental or harmful to the patient.

Determining the approach to the end-of-life was not understood through patient choice, or as something that naturally happens, but through the practice and actions of doctors and other members of the healthcare team. The patient is not acknowledged as dying unless there is a decision to do so. It is noteworthy that patient request has not emerged as a theme from analysis of the data, suggesting it is possibly not seen as a driver for this, as other authors have documented that patient wishes are one reason for ongoing "futile" care (Willmott et al., 2016) and that lack of knowledge of patient wishes can complicate decision-making (Charman and Esterhuizen, 2016).

It is also noteworthy that doctor's decision-making emerged as a prominent theme in understanding the approach to the end-of-life, rather than, for example, occurring via communication (Schofield et al., 2006) or other patient-centred concepts (MacArtney et al., 2015). Interestingly, previous researchers have explored end-of-life care framed in the context of the doctor's decision-making. For example, Charman and Esterhuizen (2016) investigated influences on oncologists' decision-making for patients in their last weeks of life. Similarly, Canadian researchers have performed a review of end-of-life care among doctors in postgraduate training linked to decision-making (Gorman et al., 2005). They found postgraduate trainee doctors had low confidence in their own end-of-life decision-making abilities and had variable understandings of significant concepts related to end-of-life care. These studies contrast with my findings, as they focus on decisions made about the care of patients already known or deemed to be dying, rather than investigating understandings of when a patient is approaching the end-of-life, and how decisions influence this.

Taylor et al (2017) investigated the recognition of dying among UK senior and junior cardiology and oncology doctors and nursing staff with reference to decision-making

theory, which aligns with the focus of the study presented in this chapter. Taylor et al explicated six emerging themes which related to recognising dying to decision making. These findings complement my findings, in so far as the patient may be deemed to be dying through a process of decision-making. In contrast to my findings, the authors delineated and quantified individual items of information which informed the participants in recognising dying, including physical symptoms and signs, which they postulated were used as items of information by the individual. My study has taken a broader view of the whole process of the approach to the end-of-life, examining what ways of understanding this may encompass, rather than pre-supposing a single concept (recognising dying). Additionally, Taylor et al.'s study has assumed a learning model which is aligned with cognitive, clinical decision-making, whereas my study has taken a socio-material lens, considering knowledge influenced through interaction with workplace factors. I build on my findings further, by exploring how the practice of doctors facilitates and influences these understandings – as will be discussed below.

5.3.3. Transitions in training

This study allows consideration of the influence of undergraduate and postgraduate training on current practice of doctors. Findings indicate that, in general, participants did not perceive themselves as prepared for care for patients approaching the end-of-life by their undergraduate studies. Perceived challenges in preparation for practice as doctors are well documented (Illing et al., 2008; Cameron et al., 2014; Monrouxe et al., 2015; Lefroy et al., 2017; Williams and Ledger, 2019). Many authors have explored and criticised undergraduate teaching about palliative care (Gibbins

et al., 2009; Gibbins, et al., 2011; Masud et al., 2014; Linklater, et al., 2014; Walker et al., 2017; Boland et al., 2019). Concern has been raised about variability in duration and content of palliative care teaching at different UK medical schools, and questions raised about whether increased undergraduate teaching can increase competence in palliative care (Mason and Ellershaw, 2010; Crawford and Zambrano, 2015). There are prevailing opinions among junior doctors and their trainers that junior doctors are not prepared to care for the dying (Bowden et al., 2013; Barclay et al., 2015). Factors at an undergraduate level which may contribute to lack of preparation include lack of exposure to dying patients, lack of relevant assessments, and variability in the volume of teaching (Gibbins, et al., 2011).

This corresponds with findings presented in this chapter. For most participants, they had not had the opportunity as medical students to see dying patients in the acute hospital setting. Learning about end-of-life care, when it happened, was situated in specialist palliative care settings. This potentially prevented them from seeing the connections between acute illness and dying (the approach to the end-of-life), and how central this was part of the role of the doctor in general medical settings.

Findings suggest that undergraduate education had led participants to consider that the purpose of medical practice to effect cure. Having commenced practice as doctors, all participants described having encountered patients approaching the end-of-life in hospitals, which had informed their understandings of the approach to the end-of-life. After graduation, participants moved from an expectation of cure to an understanding that in some cases patients may not be cured, despite medical treatment. It was after beginning practice that opinions developed of what constituted good care of these patients.

Since almost all medical departments will have had patients who were dying, it is not clear from the data why most participants were not involved in care of such patients as medical students. It raises questions of whether it was the students themselves who avoided this, or whether there was 'gatekeeping' by other healthcare professionals. However, the findings contribute to the argument that medical schools do not value teaching and assessing about care of the dying (Gibbins et al., 2011) and support the idea of medical education and training preferentially presenting clinical medicine as certain, limiting exposure to clinical uncertainty (Cooke, Doust and Steele, 2013; Malterud et al., 2017). Medical students may engage more with straightforward cases than difficult ones (Ribeiro et al., 2018), as diagnosis of dying and other elements related to the approach to the end-of-life have been noted to involve much challenge and uncertainty (Christakis and Lamont, 2000; Clarke et al., 2009; Wilson, et al., 2013; Kennedy et al., 2014; Etkind and Koffman, 2016). It would be interesting to consider whether the perceived lack of importance attributed to care of patients approaching the end-of-life is manifest explicitly or more implicitly in medical schools, e.g. whether it lies in the explicit curriculum, hidden curriculum or both (Lempp and Seale, 2004).

The finding that beginning practice leads to change or development in understanding of patient care has parallels with existing literature discussing the significance of transitions. In this context, *transition* denotes how one experiences continuity and/or transforms when becoming something or someone new (Beach, 1999). Transitions which involve an individual taking on greater responsibility have been associated with compromised performance and adverse outcomes across professions (Morris and Blaney, 2011). Within medicine, the shift from medical student to working as a doctor has been identified as a significant transition, but other major transitions may include

medical students moving from pre-clinical medical studies to learning in the clinical environment; from junior doctor to consultant (Cameron et al., 2014). These medical transition points are intensive periods during which the students or doctors both learn *about* providing patient care and *from* providing patient care (Teunissen and Westerman, 2011b) and develop or change their professional identity (Bhat et al., 2018). At times of transition, the learner may re-learn what they thought they knew (Teunissen and Westerman, 2011b). These transition points are recognised to be areas of significant challenge (Teunissen and Westerman, 2011a; Westerman et al., 2013; Boivin et al., 2016; Williams and Ledger, 2019) and may be detrimental to patient safety (Jen et al., 2009; de Feijter et al., 2011).

Despite such a transition, there is still lack of one consistent conception of the approach to the end-of-life, and it may depend on different times, places and people. This corresponds with junior doctors experiencing several transition points during their training, even within the same training year or grade, e.g. when rotating between different departments with different systems, learning environments and values (Kilminster et al., 2011). Organisational factors and quality of feedback – which can vary – may make transitions more difficult (Cameron et al., 2014). Kilminster et al (2011) have argued that transition periods should be acknowledged and supported as critically intensive learning periods. Correspondingly, based on my findings, there may be benefit to continuing to support the transition from students to practicing doctors (Brennan et al 2010), however, this is not the only significant transition point. If greater support is needed at times of critical transitions, this should include all transitions, e.g. between one department and another, or transitions between working with one consultant to another with a different set of expectations.

The findings presented in this chapter have gone further than existing literature because they have considered not only care of the dying or palliative care per se, but the approach to end-of-life in the general medical setting. The dearth of perceived preparedness is perhaps unsurprising, however previous literature (such as that discussed above) have taken positions suggesting that the educational problems and solutions lie *in advance* of practice. In the study presented here, undergraduate preparation was not a significant influence on current practice of participants. Learning to care for patients approaching the end-of-life had not developed at an undergraduate level. I therefore argue that the findings further support this thesis in taking a position which rejects the acquisitive view of learning (see Chapter 2) and considers learning through practice (or knowing-in-practice).

I do not mean that teaching and learning about palliative medicine at undergraduate level are unhelpful or negative. Certainly, teaching and exposure to palliative care as an undergraduate level increases awareness and competence in palliative care (Crawford and Zambrano, 2015). Based on my findings, perhaps medical schools are exacerbating the dichotomous view of end-of-life care as being separate from general or acute medical care, making it difficult for new graduates to understand how to provide care in general medical settings. This potentially supports arguments for undergraduate medical education incorporating care of the dying across specialties, not compartmentalised as teaching on palliative or end-of-life care (Linklater, et al., 2014; Boland et al., 2019). This may involve teachers and trainers across clinical disciplines actively articulating cases of patients approaching the end-of-life to medical students in order to assist understanding of how this may happen in different departments and with different disease groups. This may represent the "cognitive apprenticeship" model which intends to make the thinking of the trainer

visible to the learner (Woolley and Jarvis, 2007). However, expecting junior doctors to be prepared for care of the dying by graduation is unrealistic (Bowden et al., 2013). I argue that learning to fulfil the role of caring for patients approaching the end-of-life is far more expansive than what is learned in advance of fulfilling the role.

At points of beginning practice – and throughout practice – transition points are intensive and critically important to the learning of doctors and can be risky for patients. By supporting doctors in transition, there may not only be value to education and professional development, but to patient care. Although improving undergraduate training may have some influence on preparing for transition, this may only address one transition. This raises the important question about what it is that influences these doctors in practice (and different practices) to consider that a patient is approaching the end-of-life, as will be discussed.

5.3.4. Differing roles and hierarchy

Findings indicate doctors play important roles in care for patients approaching the end-of-life, but roles differ depending on times and settings. Participants considered themselves as junior within the multi-disciplinary team, and that this was evident to all other members of the team. Being junior was explained as having relatively low levels of responsibility, being less knowledgeable, less experienced, and able to offer less to patients and their relatives. In contrast, more senior doctors had greater responsibility, with the most senior doctors (consultants) having ultimate responsibility. Participants contrasted themselves with consultants who they deemed to have a much greater level of expertise and experience. Senior doctors were

responsible for the ‘decision’ that the patient was deemed to be approaching the end-of-life and/or deciding to change the goals of treatment for that patient accordingly. Foundation doctors are ostensibly present to enact tasks based on the decisions made by others. Although they were often the first to see deteriorating patients and to alert more senor doctors to patient deterioration (“stabilise and get help”), it was not seen as their role to declare or decide that a patient was approaching the end-of-life.

However, enacting the role of the foundation doctor within these limits led to tensions. Participants felt they lacked the means to appreciate when a patient was approaching the end-of-life. Conversely, at other times, participants identified that a patient may be approaching the end-of-life and questioned the goals of treatment for that patient. At these times they may struggle to identify the correct treatment plan and feel dissatisfaction if there was a mismatch between life-prolonging actions and their doubts about whether this was in the patient’s best interests. Similarly, this could be seen on occasions when the consultant had prematurely or erroneously deemed that a patient was approaching the end-of-life and stopped life-prolonging treatments.

Participants varied in their comfort with questioning consultants about the goals of treatment: they generally did not see it as their place to do so but felt compelled to at times. Their willingness to do so varied depending on the consultant. Generally, confidence in questioning consultants increased with time and experience. Trying to understand why decisions were made was perceived as an essential part of learning. Frustration was experienced when they did not agree with or understand decisions.

Furthermore, boundaries of responsibility were not always clearly defined and were seen to shift. The expectations of the junior doctor and how far s/he should go in

patient management varied depending on place (e.g. different departments) and time (e.g. OOH working). The number and distribution of doctors change at various times of day, and so depending on their shift pattern, the patients for whom foundation doctors are responsible for also differs. When working OOH, consultants are normally not present in the hospital and only contactable via telephone. Participants describe that the most senior doctor physically present – and therefore the one with delegated highest level of responsibility – is normally the registrar (see Figure 1, Chapter 1). Ostensibly, they are providing oversight for the foundation doctor, but they may not be in the same location and there may be time periods without communication between registrar and foundation doctor. This reflects that the level of direct supervision in place for junior doctors differs at different times (Morris and Blaney, 2011). During OOH working, foundation doctors are more commonly called to review acutely unwell patients, and because they are covering a wider distribution of patients, they often are not familiar with the patient or the consultant's prior decisions. For junior doctors, there is a tension between learning to practice as a doctor and maintaining patient safety (de Feijter et al., 2011).

There was an awareness among participants that they may not be able to provide a high level of patient care. Participants described times where neither they – nor the registrar present – were willing to act above their station and change the goals of treatment. This illustrates a notion of deferring of decision-making related to altering treatment goals at the end-of-life until senior doctors are available (Conn and Berry, 2010). Although participants believed the patient may suffer from the disconnect between day and OOH working, and delays in appropriate decisions, participants were generally reluctant to speak to consultants OOH about such decisions. This corresponds with previous research which identified fear of waking senior doctors

overnight and of criticism prevented junior doctors from escalating concerns (Rotella et al., 2014). The view that these decisions were not "something that you could phone a consultant at 4am to ask them" may represent structural barriers – which include power disparities, fear of reprisal, lack of mutual respect – to raising concerns about patient safety or welfare (Rowland, 2017). This aligns with existing literature that purports trainees consider professional credibility in addition to clinical implications when seeking support (Kennedy et al., 2009).

Hierarchy among doctors (including within medical training) is widely acknowledged. Medical doctors enact different roles and there are gradations of authority, learned by explicit and implicit rules, and socialisation within a culture with tradition and cultural norms (Ratanawongsa, Kern and Barker, 2005; Martimianakis et al., 2015). Junior doctors are positioned under the authority of consultants (Crowe, Clarke and Brugha, 2017). However, my findings indicate that foundation doctors are only sometimes acting as an apprentice or a learner under the general oversight of their trainers. At other times the amount of responsibility and autonomy afforded to them (see Billett, 2001a) shifts drastically. Foundation doctors are nominally junior with little knowledge and responsibility, present for performing the most perfunctory and basic medical tasks, but are often required to work without direct contact with senior doctors. During these times they are expected to initiate treatments, and it is their responsibility to decide when and what to discuss with more senior doctors, and the urgency with which they "get help". There are significant effects on the patient if their actions lead to a change or re-evaluation for the goals of treatment in a patient. This stands in contrast to the view of legitimate peripheral participants as first described by Lave and Wenger (1991), i.e. that medical learners are participating in practice in a peripheral way and under the close guidance of more experienced practitioners.

This also differs from a model of adjustable, trainee-specific supervision where the senior doctor balances trainee autonomy against patient need in a dynamic way, tailored to individual learning needs (Piquette, et al., 2015). It appears responsibility is not static and does not increase in a predictable or time-wise way tailored to the learner but varies significantly depending on systems factors such as time of day and immediate availability of other doctors. Ultimately, if there are no other doctors present, foundation doctors are left in a position where they will have to act with greater responsibility, regardless of experience or perceived competence (Zukas and Kilminster, 2014). I therefore agree with Fuller et al (2005) that Lave and Wenger's model of legitimate peripheral participation may explain a component of workplace learning of junior doctors but does not offer a total explanation.

Foundation doctors perform important roles, and, in the context of this thesis, perform essential and dynamic roles in care of patients approaching the end-of-life. However, the importance of this role is perhaps unacknowledged or downplayed – even by the foundation doctors participating in this study. It is worth noting that very few published clinical guidelines reviewed in the process of this thesis relating to the approach to the end-of-life (including those analysed in Chapter 3) contained specific mention of the role of the junior doctor. More generally, in recent publicised disputes regarding the junior doctors' contract in the NHS in England, one of the issues raised by campaigners was the ignorance and lack of appreciation of the important work of junior doctors. Many lay people were apparently unaware that junior doctors are not employed in a hands-off educational capacity but are in fact the doctors who are assessing and initiating (often life-saving) treatments, frequently several hours before a consultant will assess the patient (Goddard, 2016). In parallel, my findings suggest a disparity between the perceived value attributed to the junior doctor in care of

patients approaching the end-of-life within the medical community, the general public, and – based on how participants describe their role – perhaps, foundation doctors themselves. Further discussion of the influences on the foundation doctors performing and learning in practice is given in the next section.

5.3.5. Learning in the workplace

Within modern workplaces there are increasing levels of systemic organisation in response to demands for efficiency (Fuller and Unwin, 2014). The challenging environment in which junior doctors work, learn and train is one that has been discussed greatly. For example, junior doctors work in shift patterns which have been associated with detriment to junior doctor welfare (McIntyre et al., 2010) and learning (Devitt et al., 2018), and poor continuity of care and communication between shifts (Al-Qurainy, et al., 2009). Excessive workload in postgraduate training may limit workplace learning (Dornan, 2012) and lack of organisational support may contribute to rates of anxiety and depression in junior doctors (Kerrien et al., 2015). Indeed, the tightly orchestrated changeover system in UK training, where most new doctors begin work as foundation doctors, and more experienced doctors-in-training are promoted to the next grade (annually occurring on the first week of August), has been claimed by some to be associated with increased patient harm (Jen et al., 2009). The findings presented in this chapter indicate that it is in this challenging workplace environment that care of the patient approaching the end-of-life is learned.

This aligns with findings from Price and Schofield (2015): in a study of UK core medical trainees[4] they elicited that participants learned to care for dying patients in hospital *on the job*. I have gone further by considering learning about care of the patient at the approach to the end-of-life and providing a detailed analysis of what factors influence the workplace learning of junior doctors in this context, as will be expanded on here.

Participants learned to perform the role of caring for patients at the approach to the end-of-life, and their confidence, comfort and understanding of the role increased over time spent and experience gained in the workplace. This fits with existing literature indicating junior doctor confidence and perceived competence increases during foundation training (Mason et al., 2013).

Foundation doctors spend more time in direct contact with patients (including dying patients) than consultant doctors, and nurses spend more time than foundation doctors. Interactions with other professionals were major influences on participants' development as practitioners, particularly those with consultant doctors. This aligns with existing literature that interactions and conflicts within healthcare teams affect end-of-life care (Coombs et al., 2012). The participants assumed confidence, competence and expertise on the part of their consultant colleagues. Nurses also influenced this workplace learning. The importance of collaboration between healthcare professionals in provision of the appropriate end-of-life care for individual patients has been previously established (Bellamy et al., 2018). In the present study, nurses were perceived to know patients better than foundation doctors and able to identify when the patient was approaching the end-of-life. However, deciding to alter

[4] Grade of junior doctor who is undergoing core medical training; they have completed their foundation training, and are starting to specialise within internal medicine (see Figure 1, Chapter 1).

the goals of treatment rested with medical doctors. Participants' accounts revealed that nurses would raise concerns about the goals of treatment. Existing literature corroborates that nurses care about and are involved in care at times when patients are approaching the end-of-life, and may act to mediate between patient and doctor and to attempt timeous changes in medical plans (Broom et al., 2016; Massey, et al., 2016). However, there are documented challenges for nurses in navigating their close nurse-patient relationship against a perceived power imbalance with doctors (Broom et al., 2016; Chua et al., 2019). In the present study, input from nurses was often perceived as trying to influence the actions of medical staff, and may be regarded as helpful, but at other times as interference or undermining. It was difficult for foundation doctors to balance their biomedical approach and different professional responsibilities against the views being communicated by nurses.

The organisation of the workplace was a further influence on learning. Organisational factors are recognised as sometimes contributing to poor patient care and medical errors (Kohn, Corrigan and Donaldson, 2000). For end-of-life care, systems factors in hospital have been identified as potentially detrimental, including increasing specialisation leading to system-based or goal-orientated treatments rather than holistic, person-centred care; time pressures which make it easier to simply continue a patient's treatment rather than re-evaluate (Al-Qurainy, Collis and Feuer, 2009; Levack, 2014; Willmott et al., 2016). These findings are reflected in the present study which has gone further, by presenting analysis of how organisational factors influence practice-based learning. In their role, foundation doctors utilised methods to facilitate their practice when patients were approaching the end-of-life. This was notable during OOH working, as these times provided a significant challenge to fulfilling their role. During these periods, other doctors were not immediately available and there

were changes in quality and distribution of responsibility (discussed in detail above). During OOH, foundation doctors were often responsible for assessing sick and deteriorating patients who they did not know. This may mean the foundation doctor was required to make decisions and/or communicate decisions for which they felt unfamiliar and uncomfortable, which was frustrating. Input from nursing staff who were familiar with the patient was influential at these times.

Additionally, shifts were demarcated by handover and hand-back of responsibility for patient care at the starts and ends of shifts. Communication which occurred via the handover could provide useful information about patients who may deteriorate, and what to do in such circumstances. Documentation was another important tool to facilitate understanding the patient, what was expected and what might be reasonable in order to enable their decision-making. Equally, the lack of adequate communication between the patient's normal medical team and those working OOH was a source of frustration. The process of handover itself caused foundation doctors to consider whether the patient was approaching the end-of-life and what may be appropriate treatment plans. Documentation in patient notes could be used as a communication tool by the OOH to call for decisions to be made by the day team.

Foundation doctors were also influenced by emotional reactions. This is perhaps unsurprising, as participants indicated that they care about providing a high standard of care for their patients. Emotional reactions to challenging experiences among junior doctors are well documented (Rhodes-Kropf et al., 2005; O'Donnell et al., 2012; Lundin et al., 2017), and junior doctors may experience greater emotional labour than senior doctors (Monrouxe et al., 2015). Among doctors generally, emotional reactions to death and dying are well recognised (Redinbaugh et al., 2003;

Kelly and Nisker, 2010; Brennan et al., 2010). The effects of emotional reactions should not be neglected, since they can affect meaning-making (Kilbertus, et al., 2017), clinical decision-making, quality of patient care (Resnick, 2012), and may contribute to clinician depression, burnout, attrition from the profession, and suicide among doctors (Monrouxe et al., 2015). In the present study, emotional reactions were stronger when the case of a patient dying was found more upsetting, e.g. younger adult or child patients; the doctor had a longer or more involved relationship with the patient. However, the findings also indicate emotional reactions do not only occur when realising a patient is dying, but also in reaction to patients not receiving appropriate treatment. Of note, not all participants discussed their emotional reactions in depth, possibly suggesting that emotions did not influence all doctors in the workplace. Another interpretation is that some participants wished to avoid discussion of their feelings during the interview or did not consider emotions to be relevant. For those who discussed their emotional reactions, they found it easier to resolve distress and learn effectively from cases when they had opportunities to discuss them with colleagues. This corresponds with arguments that healthcare professionals should have opportunities to de-brief following the death of a patient (Keene et al., 2010).

It is noteworthy that the influence of patients and family wishes did not emerge as a theme related to influence on learning in analysis. This corresponds with the finding in Chapter 3 that patient wishes are not found to be a significant influence on understanding the approach to end-of-life and corresponding decision-making. Although there was an acknowledgement that decisions should be made in the patient's best interests, and for an outcome that would be desirable to the patient, participants also felt that it is not possible for patients and their relatives to fully

understand which medical actions or decisions they would want enacted. This is interesting as the need for active involvement of patients in care decisions at the end-of-life has been highlighted (The Scottish Government, 2008; 2015), there is increasing emphasis on shared decision-making generally within medical guidance (General Medical Council, 2008; Royal College of Physicians, 2013; Staveley and Sullivan, 2015), and the actions of staff around the time of the patient's death can have a lasting effect on the bereaved relatives (Donnelly and Dickson, 2013).

The findings have indicated that different members of the multi-disciplinary team play important but differing roles in the care of patients approaching the end-of-life, and foundation doctors form an important part of that team. Foundation doctors operate in a system that does not easily facilitate changes in goals in the patient care for patients approaching the end-of-life, and they must learn to negotiate their interactions with social others and available resources in order to perform their role and provide optimal care to patients approaching the end-of-life. Barriers to providing perceived optimal care are frustrating and upsetting, and as familiarity increases in the workplace, the practitioner increasingly questions practice. The wider implications of these findings are discussed in the next section. After this, the contribution of these findings to advancing this thesis are discussed.

5.4. Wider implications of findings

In addition to advancing this thesis, this study has wider implications. Firstly, findings indicate understandings in patient care among foundation doctors which potentially contrast with dominant attitudes espoused in end-of-life care literature. Most patients who die in a healthcare setting do not do so in a setting with a specialism for end-of-

life care. Authors have argued for the importance of end-of-life care being made the business of all professionals in hospitals (Oliver, 2016), however participants saw a disparity between standard hospital care and care for patients approaching the end-of-life. This perceived disjointedness between different approaches to care suggests there are ongoing barriers to patients receiving adequate end-of-life care in the general hospital setting, and that should be an ongoing focus for improvement.

The perceived dichotomy between standard care and care for the patients approaching the end-of-life is evident in confusion when there appears to be a combination of approaches, and when patients revert from being treated as dying back to standard care. This relates to one of the widely-publicised criticisms of end-of-life care in UK hospitals at the time of the Liverpool care pathway (LCP) controversy. Although the LCP was intended to facilitate high quality end-of-life care for in-patients in the general hospital setting, reports of its misuse led to it being rescinded. One area of misuse was a perceived absolutist interpretation of the guidance which meant that the goals of care for patients was not re-evaluated, leading to patients still being treated as if they were dying even if their condition improved (Neuberger, 2013; Seymour and Clark, 2018). However, despite the LCP no longer being used in UK hospitals, difficulties understanding that decisions about the approach to end-of-life are complicated, dynamic and not absolute may persist. Furthermore, the findings indicate a perception that difficulties with accepting and talking about dying do not only exist among the general public (Boyd and Murray, 2014) but among doctors as well. This gives greater weight to initiatives such as Realistic Medicine (The Scottish Government, 2015) which aim to encourage healthcare practitioners to actively consider the overall goal of care.

Another noteworthy finding has been the influence of empathy on junior doctors' understanding of the approach to the end-of-life, demonstrated in imagining themselves in the position of the patient, patient's relative and/or the consultant decision-maker. One widely held concept has been that empathy generally declines during undergraduate training (Colliver et al., 2010). The contribution of empathy to the understandings of newly graduated doctors is interesting, as these doctors have more recently completed their medical degrees. It potentially contests the view of the creation of un-empathetic, cynical doctors by medical schools. It would be interesting to investigate how empathy is involved in understanding the approach to the end-of-life among medical doctors at different stages of clinical training and experience in the future.

Although this thesis does not have a central focus on undergraduate training, there may also be potential implication of these findings for teaching of medical students. There is a seeming lack of preparation for dealing with uncertainty. Intolerance of uncertainty is a problem with medical practice (Cooke, et al., 2013), which goes beyond only care of patients approaching end-of-life. However, learning to become part of a profession is also learning to navigate, and help patients navigate, uncertainty (Evetts, 2013). This indicates that it is insufficient for medical schools only to teach and assess about the more certain areas of medical care, with clear right and wrong answers. The findings also have implications for consideration of professional identity among doctors and medical students, and the impression of healthcare which is presented to medical schools. Foundation doctors may have graduated from medical school without a developed understanding of the approach to the end-of-life and its relevance to medicine and patient care. If newly graduated doctors have not developed their understandings at an undergraduate level, this

raises questions of whether the medical school is presenting an impression of patient care which is realistic. Realising how important end-of-life care is to the work of the doctor and to healthcare may cause a challenge to the professional identity of new doctors, if this is at odds with their pre-formed ideas.

The findings also indicate that foundation doctors are operating with varying degrees of autonomy, particularly OOH, and there are various factors which influence their perceived ability to be supported. This is important, since it has been acknowledged that context and professional culture can influence clinical reasoning (Peters et al., 2017), and the dependence of quality of patient care on the availability of clinical supervision for junior doctors has been asserted (Piquette, et al., 2015). Considering how the training environment supports junior doctors is pertinent to end-of-life care, given the great number of people who are dying in medical settings and how central junior doctors are to their care. Identified characteristics of an environment where patients receive good quality end-of-life care have been discussed (Waller et al., 2008; Gott et al., 2019) but these discussions tend not to include professional culture or support for trainee doctors. Discussions of what constitutes an environment where patients receive good quality care – including good quality end-of-life care – should acknowledge important roles played by junior doctors, and be one in which foundation doctors are supported in their role. Such environments should also consider the understandings and practice of other healthcare professionals, particularly nurses. Potentially, workplace environments where junior doctors feel supported by senior doctors and nursing colleagues, and where questions of the goals of treatment in patients approaching the end-of-life can be openly raised among the clinical team, may provide better learning and a better standard of patient care.

5.5. Advancing the thesis

This thesis explores understandings of doctors learning about patients approaching the end-of-life in the workplace. This chapter has presented themes related to how foundation doctors conceptualise the approach to the end-of-life, and how they understand and learn about patients approaching the end-of-life. The findings indicate foundation doctors operate in a perceived system where the patient is expected to be cured. The norm is for care with life-prolonging and/or curative intent, and it contrasts with care associated with patients approaching the end-of-life. Outwardly acknowledging the approach to the end-of-life and making corresponding appropriate treatment changes occurs via a deliberate decision by doctors. Understanding deviations away from standard goals of medical care – and why/when these may be appropriate – had not been developed before commencing work as doctors, becoming integrated in the workplace. The doctors then became able to form their own understandings of whether a patient is approaching the end-of-life and formed negative opinions of patient care then when there is no appropriate acknowledgement of or change in goals of treatment. Newly developed understandings of the approach to the end-of-life are influenced by their perceptions of the patient, views on medical treatments, and empathy. Understandings are facilitated by their knowledge and experience of the individual patient and their care, and more challenging when the patient is not known to the doctor.

The data from this study were analysed separately from the qualitative content analysis of literature presented in Chapter 3, and yet there are clear parallels between findings. Based on both my analysis of the extant literature, and separate analysis of my empirical findings in this chapter, I argue that doctors do not understand the

approach to the end-of-life as a discrete entity, nor as a single, consistent concept. Instead, these understandings are constructed and/or influenced by subjective judgements made from their perspectives as practicing medical doctors. The findings of this chapter have gone further by indicating that these understandings are not developed at an undergraduate level, but after commencing practice. This chapter therefore further cements the view of the learning about patients approaching the end-of-life through the lens of work-place learning. It has therefore further situated this thesis within socio-material learning and considering of education linked to practice. I argue against the cognitive view of preparation or know-how in advance of practice, to a focus on how working as foundation doctors and systemic factors in the workplace inform, influence and challenge learning in practice.

It is therefore vital to consider the practice of doctors in order to investigate their learning and understanding. The role played by the doctor in care of patients approaching the end-of-life is important and is often challenging and emotive. Despite nominally having minimal responsibilities, the boundaries and responsibilities of the role are inconstant, and vary based on factors external to the individual doctor. Multiple workplace factors influence the doctor in practice, meaning that learning to care for patients approaching the end-of-life is an activity involving interactions with other healthcare workers, and with several other tangible and intangible organisational factors.

By incorporating Cultural Historical Activity Theory (CHAT) these social and material influences can be considered as mediating the practice of the subject. This thesis will next move on to examine the findings through the lens of CHAT. The findings allow identification of aspects of activity where tensions lie, and postulation of which may be changed to improve practice. By considering how they can better facilitate

learning and practice of medical trainees, the organisation may benefit both the worker and patient care, and move the onus of responsibility for workplace learning away from medical schools and the individual learner.

5.6. Limitations of analysis

In Chapter 4, I discussed the limitations of the study design. This section will encompass discussion of limitations of the analysis and claims I have made based on the findings. Firstly, the study can be criticised for the relatively low level of theoretical input. As discussed in Chapter 2, theory is advantageous for the design and interpretation of qualitative research, yet this analysis was approached inductively without a pre-established framework. To mitigate this, my analysis was sensitised with theories of critical realism, socio-materiality, and CHAT. I have also discussed findings with reference to existing literature, in order to contextualise them in the empirical and theoretical work of other researchers. However, I recognise the value of further theoretical analysis, and go on to present further analysis and discussion through the lens of CHAT in the following chapter.

Further limitations include the scope of influencing factors which have been identified on doctors learning. There are almost certainly other influences which have not been discerned, and this may have been limited by the focus on workplace learning. For example, although lack of preparation at medical schools has been considered, this study has not considered the effects of postgraduate training curricula, and self-study of doctors. Furthermore, pre-professional experiences have not been considered, although they may influence doctors' professional development (Michalec et al.,

2018). Equally, influences outside and before work may also influence the conceptualisations and practice of doctors. This is aligned with the idea of dispositions to work and learning (Hodkinson and Hodkinson, 2004) or biography of the learner (Billett, 2004). Future work should consider the influence of individual factors on understandings of the approach to the end-of-life.

A further consideration is the issue of transferability of findings (discussed in Chapters 3 and 4). Participants were undergoing a national training programme which all medical graduates must complete if they wish to practice as doctors, meaning there were likely to be similarities across the UK. I have compared my findings with existing literature, highlighting where similarities lie with research conducted in other contexts, meaning that there are likely to be further parallels. However, as my participants were practicing in South East Scotland, transferability may be limited by regional and site-specific differences. For example, during the period of this research the NHS in England adopted a new junior doctor contract which has affected their distribution and rota commitments (BMA, 2019) and may mean there are new and/or different workplace influences in learning compared to my Scottish study. Furthermore, new changes in postgraduate training (General Medical Council, 2019) which are being introduced at the time of completion of this thesis may cause further barriers to transferability. Transferring findings more widely across contexts is likely to be limited by further factors, e.g. comparing this study to practice in the United States of America which does not have a nationalised health service, and where medical schools integrate their students in wards in an apprentice-ship model (Dornan, 2012). To enhance transferability, I have provided detailed descriptions of my processes, analysis, and findings in order to enhance

trustworthiness. This allows the reader to assess how my findings compare with their own context.

5.7. Conclusions

This chapter has presented results of inductive TA of semi-structured interviews with foundation doctors. The study has fulfilled the aims of examining how the approach to the end-of-life is conceptualised by medical doctors, and exploring experiences and understandings of doctors learning to care for patients at the approach to the end-of-life, including factors which provide barriers to learning. Findings indicate that doctors operate in a system that does not easily lend itself to changes in goals of patient care which they perceive as necessary for a patient approaching the end-of-life. Doctors must learn to negotiate their interactions with social others and available resources in order to perform their role and provide optimal care to patients approaching the end-of-life. Barriers to providing perceived optimal care are frustrating and upsetting, and as familiarity increases in the workplace, the practitioner increasingly questions practice.

The next chapter will build on the findings presented thus far – here, and in Chapter 3 – using CHAT to develop a theoretical explanation for the learning of doctors about patients approaching the end-of-life. This will lead to further discussion of the systemic challenges to learning and practice, and how these challenges may be overcome.

6. Theorising the workplace learning of doctors using Cultural Historical Activity Theory

6.1. Introduction

This chapter aims to develop a theoretical explanation of the learning about the approach to the end-of-life among doctors. Thus far in this thesis, research findings have been produced through inductive processes. In order to deepen understandings of how the approach-to-end of life is understood in practice, I adopt a socio-material framework: Cultural Historical Activity Theory (CHAT). Chapter 2 explains this theory in detail, the rationale for employing it in this thesis, and how this aligns with the philosophical underpinnings of the research. From my critical realism (CR) ontological position, events are caused by interactions of social structure and agential causal power (Elder-Vass, 2010b). In line with CR, this represents a combination of further modes of reasoning: abduction (theorising mechanisms which exist to explain events) and retroduction (theorising about what the world must be like for the mechanisms to exist, and for others not to exist) (Edwards, et al., 2014b). In other words, this is adding theory to data.

In this chapter I will draw upon CHAT to develop a theoretical explanation of the learning of newly graduated doctors about the approach to the end-of-life. I will present the workplace learning as activity systems and elaborate on the constituent elements. I will consider where tensions arise within activity systems as contradictions, and how these contradictions cause barriers to learning and practice. Lastly, I will discuss the findings in the context of this thesis, and potential wider

implications. The discussion will include how CHAT allows consideration of how to improve future learning and practice in care of patients approaching the end-of-life.

6.2. Activity Systems Analysis

To theorise the workplace learning of doctors using CHAT, I examined the data from the preceding studies with reference to Activity Systems Analysis (ASA) as described by Yamagata-Lynch (2010). I undertook the process described in Table 10, recommended by Yamagata-Lynch, by asking the following questions of the data presented in Chapters 3 and 5.

Table 10. The Eight-Step-Model of Activity Systems Analysis, adapted from Yamaga-Lynch(2010)

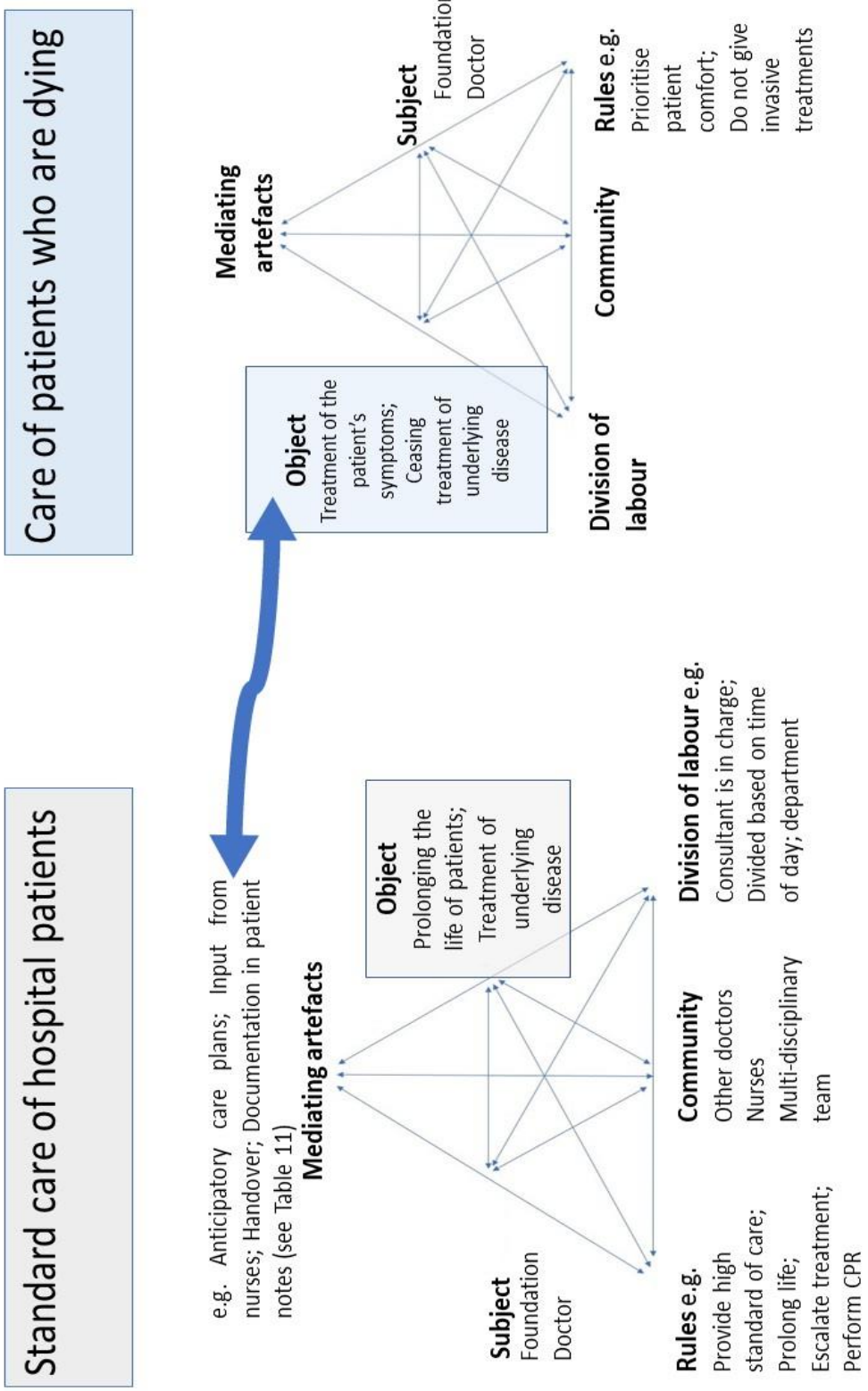
Step in ASA		**Question to ask of the data**
Step 1	Activity of interest	What sort of activity am I interested in?
Step 2	Objective	Why is the activity taking place?
Step 3	Subjects	Who is involved in carrying out this activity?
Step 4	Tools	By what means are the subjects performing this activity?
Step 5	Rules and regulations	Are there any cultural norms, rules or regulations governing the performance of this activity?
Step 6	Division of labour	Who is responsible for what, when carrying out this activity and how are the roles organised?
Step 7	Community	What is the environment in which activity is carried out?
Step 8	Outcome	What is the desired Outcome from carrying out this activity?

An example of how I applied this to the empirical data is shown in Appendix 4. Clearly, in the busy workplace of the hospital with several interacting workers carrying out multiple actions, the system is complex. So that the ASA did not become overwhelming and complex beyond any useful interpretation, it was necessary to focus on and present only the most salient and essential aspects of systems which are relevant to the thesis (Yamagata-Lynch, 2010).

6.3. The activity system(s)

In Figure 7, I present the workplace learning of doctors about patients approaching the end-of-life as occurring in activity systems (AS). This is the first conceptualisation of the activity systems resulting from the ASA. This can also be found in Appendix 5. Examples have been provided for components of the AS which contrast most profoundly with the alternative AS. Examples are provided only for differing components in order to emphasise the most important contrasts.

Figure 7. Activity system of doctors learning about patients approaching the end-of-life in the workplace.



In order to elaborate on this conceptualisation, the individual elements of the systems are explained below. As explained in Chapter 2, within CHAT human activity is a series of processes that are contained within an activity that acts as a bounded system (Yamagata-Lynch, 2010). Although I describe the components of the AS separately, I do not intend to suggest that they are separate. On the contrary, the components should be considered as interacting with one another to create the overall bounded system.

6.3.1. The subject

The subject in the AS is the foundation doctor. How the subject interacts with their environment is represented by the bi-directional arrows in Figure 7. Foundation doctors are the most junior within a hierarchical team of doctors. They are often the first doctors to review sick patients, including out-of-hours (OOH). All foundation doctors are required to provide care for patients approaching the end-of-life in their work.

The motivation of subjects is to provide high quality care for patients in all cases. It is after beginning to work that the subject learns to practice as a doctor. Although they are familiar with the principles, it is only over time working in the system that they move from abstract to concrete understandings. This involves learning to interact with artefacts which facilitate their activity. In Vygotksian terms, this represents *internalisation*: how individuals become embedded in practices of a system and process what they learn through mediated action (Fuller and Unwin, 2014). In CHAT, this may be considered a Zone of Proximal Development (ZPD) that has been incorporated to represent the distance between learners simply learning

things by rote without understanding the purpose, and later coming to understand the deeper and wider significance of actions (Vygotsky, 1978).

As internalisation occurs, the subject understands the significance of different operations and actions, and the overall object with which these are culturally embedded. They understand that care required for patients approaching the end-of-life is different from the standard care of patients. They form opinions of the care that should be indicated for the patient and the associated actions, which may contrast with the actions they are expected to carry out. At times where they feel the care is inappropriate, the subject experiences frustration and possibly negative emotional reactions (although they recognise the importance of controlling their emotions). Through the process of *externalisation*, subjects start to question why things are done in certain ways in the workplace (Engeström, 1987). Foundation doctors may feel powerless to change things when they act under the expectations and instruction of others. Nevertheless, they begin to internally (and sometimes outwardly) question practice and identify contradictions with the system.

6.3.2. Mediating artefacts

Foundation doctors skilfully interact with the artefacts or tools (which includes theories and concepts) (Wheelahan, 2004) used in their practice. Examples of mediating artefacts – and signs which are used as tools – are displayed in the following table. The relevant chapters where the results are referred to are provided.

Table 11. Examples of mediating artefacts

	Examples	**Relevant results chapter**
Artefacts	Anticipatory care plans	Chapter 3
	Skills in care of the dying	
	Knowledge of typical disease trajectories	
	Existing knowledge of the patient	Chapter 5
	Patient age	
	Patient quality of life	
	Number of patient co-morbidities	
	Patient wishes	
	Instructions / advice / guidance from consultants	
	Documentation in patient notes	
	Opinions and instructions of other doctors	
	Input from nurses	
	Handover process	
	Shift pattern / time of day	
	Debriefs with senior colleagues	
	DNACPR orders	Chapters 3 and 5
Signs	Perceived increasing needs of the patient / palliative care needs	Chapter 3
	Worsening patient symptoms	
	Judgements of reversibility of patient condition	
	Sense of own limitations	Chapter 5
	Noticing recurrence in patient infections	
	Perceived worsening in patient condition despite treatment	
	Imagining oneself in the position of the patient or patient's relative	
	Knowing one has done everything possible for a patient	
	Judgements of aggressiveness of treatment	Chapters 3 and 5
	Judgements of appropriateness of treatment	

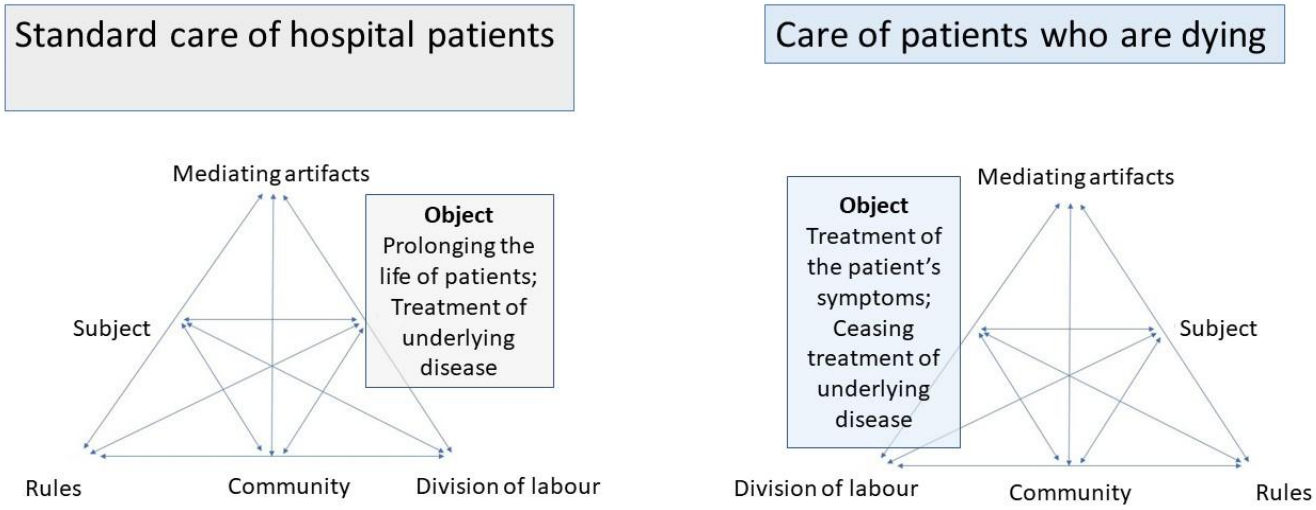
Artefacts may be psychological (e.g. interactions with others), intangible or tangible. The meaning of the interaction is negotiated between subject and artefact and affects the outcome of the activity (Wheelahan, 2004; Johnston and Dornan, 2015). A thing becomes a cultural tool when it has gained significance greater than its role in completing an immediate action, rather than as a temporary tool (Yamagata-Lynch, 2010). Tools may include social others and prior knowledge that contribute to the subject's mediated action experiences. Furthermore, once an activity is institutionalised, it may itself become a tool within that culture (Cole and Engeström, 1993).

CHAT also considers signs: these are cognitive tools which are generated from interaction with artefacts. Once a sign is generated, the subject can transform it into an enduring cultural artefact by the way in which s/he decides to continue to use and share the sign (Yamagata–Lynch, 2010). For example, foundation doctors may recognise the sign of a patient being elderly or a nursing home resident to aid them in understanding if a patient is approaching the end-of-life. These therefore take on usefulness as a tool which is beyond their simplistic meanings.

6.3.3. Object

Engeström described objects as "generators and foci of attention, volition, effort and meaning" (Engeström, 1987 p. xvi). The object is the reason why people are participating in an activity and holds all elements together in a bounded activity (Yamagata-Lynch, 2010). Objects differ from the immediate goals of the component actions within an activity. Different objects can lead to the conceptualisation of two activities as displayed in Figure 8.

Figure 8. Different systems of activity within the practice of doctors.



For foundation doctors in practice, there is an overall object of providing good care for patients. However, as they become institutionalised within the workplace, doctors understand the difference in the objects between care of patients approaching the end-of-life and standard or default care. The difference in activity, and component actions (with their component operations), between these objects come to be understood by foundation doctors based on wider cultural meaning, as internalisation occurs.

Within default patient care activity, the object is to prolong the life (if not cure) patients. Within this, activity goal-directed actions may include, for example, treatment of cancer with chemotherapy, or treatment of infection with antibiotics. The individual component operations of treating infection – which doctors come to understand as culturally embedded in this activity – may include inserting intravenous cannulae;

prescribing intravenous fluids and antibiotics; administering fluids and antibiotics. CPR is also an action specifically associated with the object of prolonging life.

In contrast, when the object is care for patients who are dying, the activity is qualitatively different from default care. Associated actions may include palliation of symptoms of dying patients (as opposed to treating the underlying disease) and withdrawal of life prolonging treatments such as renal dialysis. Component operations may include prescribing subcutaneous morphine to be administered as required for pain, and completion of a *DNACPR* form.

6.3.4. Community

Foundation doctors are part of a community of healthcare workers with different responsibilities but working collaboratively with each other. The healthcare setting is divided into specialty wards. Each patient will be in a specific department and have a named consultant who is ultimately responsible for their care. Interactions between the foundation doctor and other members of the community take on significance which mediates activity, therefore emerging as culturally specific artefacts. Although the community may be broader than this (encompassing other actors such as volunteers, the patients' relatives, and even the patient her/himself), this study of workplace learning presently considers only the professional community of interacting healthcare professionals.

6.3.5. Division of Labour

Labour is a collective activity mediated by material tools and social relationships with other humans (Johnston and Dornan, 2015). Division of labour occurs through interactions among people, producing the workplace (Gheradi, 2012). Additionally, there are doctors of differing levels of seniority and experience. There is an expectation that division of labour varies depending on this seniority. During normal working hours, the foundation doctor acts based on the instruction of senior doctors and is responsible for more menial actions and operations. It is senior doctors who are responsible for declaring the object of patient care should change.

However, for the foundation doctor, division of labour varies, and can depend on the department in which they are working, their colleagues, availability of senior support, and time of day (whether normal working hours or OOH). During OOH periods there are fewer people in the hospital and consultant doctors are often not physically located within the hospital. For example, this results in FYs being called to review patients who are deteriorating. This may also lead to foundation doctors having to make decisions out with their perceived remit or struggling to communicate effectively with a senior doctor. An example rota of a foundation doctor working in the general hospital is provided below (Table 12).

Table 12. Example foundation doctor rota, adapted from BMA (2018)

Week 1	**Shift**	**Organisation**
Mon	Long Day	During ‘day’ shifts the junior doctor has a specified base ward where they are scheduled to work 9am until 5pm. The shift finishes with handover to on-call doctors working in the evening. During ‘long day’ shifts the junior doctor is on-call for larger portions of the hospital between 5pm and 9.30pm (total 12.5 hours shift). This consists of covering both their base ward and several neighbouring wards; patients which they have already encountered and not previously encountered. The shift finishes with handover to on-call doctors working at night. Responsibilities will include being asked to conduct work that has been asked of them at handover and being called to review sick patients ad hoc and/or covering an acute receiving unit for new admissions.
Tues	Day	
Wed	Day	
Thurs	Long Day	
Fri	Day	
Sat	Off	
Sun	Off	
Week 2		
Mon	Night	During ‘night’ shifts the junior doctor works between 9pm and 9.30am (12.5 hours shift) and does not have a specified base ward. Responsibilities will include being asked to conduct work that has been asked of them at handover and being called to review sick patients ad hoc and/or covering an acute receiving unit for new admissions. They do not routinely provide care for patients already known to them.
Tues	Night	
Wed	Night	
Thurs	Night	
Fri	Off	
Sat	Off	
Sun	Off	

Within the AS, there is reliance on actions of others in order to carry out the activity. This represents *knot-working*: combinations of people and tasks changing constantly in dynamic systems in the hospital, with an inconstant centre of control and changing combinations of people and artefacts (Engeström, 2001).

6.3.6. Rules

Organisations are 'strongly structured by specialised roles [..] marked by significant authority relations between at least some of these roles' (Elder-Vass, 2010a p.152). In the general hospital, doctors act according to established social structures (Johnston and Dornan, 2015). While learning to practice, foundation doctors are learning to find their own place within the system and the rules which govern their activity. The senior doctor is ultimately responsible for making decisions. For example, it is normally unacceptable for a foundation doctor to withdraw a life-prolonging treatment without instruction or permission from a senior doctor.

Foundation doctors must also be able to adapt to differing rules, for example when moving to different departments or working with a different consultant with different expectations. For example, in a surgical ward, where senior doctors are likely to be in the operating theatre, foundation doctors have greater responsibility for patient care on the ward.

Generally, the hospital is governed by the rule that by default the intention of care is life-prolonging. The change in object of care occurs after a deliberate decision to vary from this default, and this must be instituted by senior doctors. This is represented in the rule that for patients whose heart stops beating spontaneously in

the hospital, they should by default be treated as a cardiac arrest with CPR to aim to prolong their life, unless there has been a prior decision made against this. There is a default presumption of prolonging life.

6.3.7. Cultural-historical context

The learning of the subjects within the AS is facilitated through cultural means, and rules, community and division of labour are heavily shaped by cultural expectations, which are different at different times in history (Engeström, 1987). Understanding historical context is therefore essential to understanding why activity occurs in its current form (Johnston and Dornan, 2015).

Examination of medical literature (i.e. documents with the intended audience of UK medical doctors) has indicated the wider context in which the healthcare system has been designed (Chapter 3). Healthcare in the UK is designed to facilitate cure of patients, and standard procedures are carried out with this intention. The default for patients whose condition is deteriorating is to progress to more intensive treatment. Within this cultural view, there is an underlying presumption of patient death as a failure (Greene, 2013). In recent times, some doctors and policy makers have made the case for an altered approach to medical care (e.g. Parlimentary and Health Service Ombudsman, 2014; The Scottish Government, 2015). Despite this, the cultural dominant norms remain to treat with life prolonging intent. Deciding to alter the object of practice in patient care goes against norms of the system. This is also represented in the empirical experience of foundation doctors (Chapter 5).

A further important consideration is the historical origin underpinning the AS, and why the work in the general hospital is organised and labour is divided in its current form (see table 12 above). The major policy implications which influenced the current organisation of doctors, including their shift pattern, resulted following Modernising Medical Careers (MMC) and the introduction of the European Work Time Directive (EWTD).

MMC involved a restructure of training and practice for junior doctors: jobs became centrally recruited, and ostensibly consistently structured with the aim of obtaining the same or comparable outcomes for all doctors of the same training grade. Prior to introducing MMC there were deemed to be too few consultants and UK medical training was considered nebulous and inconsistent. The previous local *ad hoc* recruitment of doctors was considered non-transparent and unfair. MMC was associated with significant controversy including claims of reduced flexibility in training and reducing training opportunities (The Academy of Medical Sciences, 2007).

The EWTD affected UK practice from 1998 to limit work to a maximum of 48 hours per week. It was fully implemented for UK medical practice in 2009. Since then, junior doctors now work much fewer hours than previously. Work is divided into shifts with clearly demarcated start and finish times. This caused the introduction of new systems to ensure doctors are available at all times to care for patients in hospital: different systems during the normal working day, and working OOH, with handover systems being in place in between shifts (Temple, 2010).

These policy changes led to re-organisation of junior doctors' work in the hospital. This has included loss of the previous 'firm structure' of doctors' work, which involved

varying grades of junior doctor being integrated into a specialty team for a prolonged time period with a specific consultant. Instead, in the current training system, continuity of the doctor-patient relationship is challenged as inevitably doctors are covering large portions of the hospital and called to review in-patients who they have not previously encountered. There are also concerns that there is poor continuity of training, and that training opportunities are much reduced (Bolster and Rourke, 2015). These cultural-historical factors have influenced the performance of the activity in its current form.

6.3.8. First conceptualisation of the activity system(s)

Figure 7 (and Appendix 5) showed the first conceptualisation of the activity systems resulting from this analysis. As established in Section 6.3.3, the difference in objects between default care and care of patients who are dying denotes two separate activities. This is represented graphically as two separate activity systems. The subject (the foundation doctor) interacts with other elements within each system in enactment of her/his role. This includes the artefacts that mediate their activity, many of which emerge from interactions with other elements of the system, e.g. input from nurses, instructions of senior doctors. Through interpretation of mediating artefacts, the foundation doctor understands how/when a patient is approaching the end of life, i.e. when the object of their care changes (or should change). Changing the object of patient care leads to a change to a different activity.

The next section will describe tensions in these activity systems, i.e. contradictions. As will be expanded upon below, this includes tensions when there is a mismatch between cultural meanings ascribed to operations and actions which are conducted

for the patient, and what the subject considers the object of activity. Incidents where there is overlap or movement back-and-forth between the activities are also described below as sources of tension.

6.4. Contradictions

The purpose of CHAT is not simply to display practice in an activity system, but to understand where conflicts and tensions lie as a basis for expansive transformation (Engeström, 1987). Contradictions in activity systems provide barriers to practice and learning. The subject becomes increasingly cognisant of contradictions within their activity as internalisation occurs, and they begin to question established practice, i.e. externalisation. If contradictions are severe, the activity may collapse and the subject may not be able to attain the object, i.e. the outcome does not align with the object (Yamagata-Lynch, 2010). Contradictions are therefore the main cause for change and development in activity systems. Contradictions are typically categorised as follows:(Engeström, 1987)

- Primary contradictions: the tension between the use value and exchange value of an element of AS, e.g. differing interpretations of norms and rules emerging from multi-voicedness within the system;
- Secondary contradictions: when two elements or more of the same activity system are in tension with each other;

- Tertiary contradictions: when there is tension between the dominant version of an activity and a new version, typically when the new version has been aimed at finding relief from one or more secondary contradictions;
- Quaternary contradictions: tensions between at least two different interacting activity systems.

Multiple contradictions have been identified in the conceptualised activity systems presented above. Salient examples are described below. Where pertinent, representative diagrams are included, in which contradictions are conventionally represented as jagged lines. Data extracts are included as representative examples. Later, this chapter postulates how these contradictions may be resolved in order to achieve expansive learning.

6.4.1. Primary contradictions

> Lukas: "I had the nurses talking to me, not to the consultant, saying, 'so if they arrest are we going to jump on their chest?' And I was like, 'well by default, yes' [..] Essentially, they wanted me to put a bit more pressure on the consultant." *(FY2, 15 months since graduation)*

Primary contradictions arise in a multi-voiced system, with multiple interacting humans and materials, when there are tensions between the use value and exchange

value[5] of an element of AS (Nunez, 2014). Primary contradictions arise within multiple elements of the conceptualised activity system. Examples are provided in the following table.

[5] Use value relates to the social need which a commodity usefully meets. The exchange value of that commodity is how that commodity is valued against other commodities. Tensions arise between use values and exchange values when there is a disparity between the usefulness of a commodity (in this context, a component of an AS) and how it is valued (Nunez, 2014).

Table 13. Examples of primary contradictions

Element	Examples of primary contradiction
Mediating artefacts	Input from nurses mediates the practice of the foundation doctors. The nurse's intention is apparently to facilitate good care for the patient who may be approaching the end-of-life, however this may always not be valued by the practicing doctor. It may be difficult to mediate nursing input, e.g. if considered ill-informed or at odds with the doctor's judgement.
	Existing knowledge of the patient is valuable for informing practice. However, knowing patients may lead to emotional reactions which may make the case more challenging for the doctor, and affect judgement, meaning, in some instances, knowing the patient is less valuable.
Rules	The consultant is responsible for deciding that the patient is approaching the end-of-life, altering the object of activity. However, the consultant is not always physically present in the hospital and there is a perceived rule that the foundation doctor would not contact the consultant at home to seek guidance on this issue.
Division of labour	Hospital labour is organised to ensure that there is always a doctor available who can attend to a sick patient. However, the doctors available at certain times of day are less equipped, able and/or willing to make treatment decisions for patients
	The most senior doctors (consultants) are ultimately responsible. However, differences exist between consultants: decisions may be consultant-dependent, or some consultants may be less able or willing to make decisions.
	Foundation doctors are often the first doctors to form assessments of patients who are sick and deteriorating. However, foundation doctors may not always realise the gravity of the patient's conditions and/or be positioned to facilitate the patient obtaining the care they need if the patient is approaching the end-of-life.

6.4.2. Secondary contradictions

> Jonah: "A patient with end stage palliative care [sic] died sitting next to a [clinical support worker] he didn't know. It's a bit shit. Crap palliative care." *(FY2, 22 months since graduation)*

Secondary contradictions occur when two or more elements of the same AS are in tension with each other.

Figure 9. First example of secondary contradiction

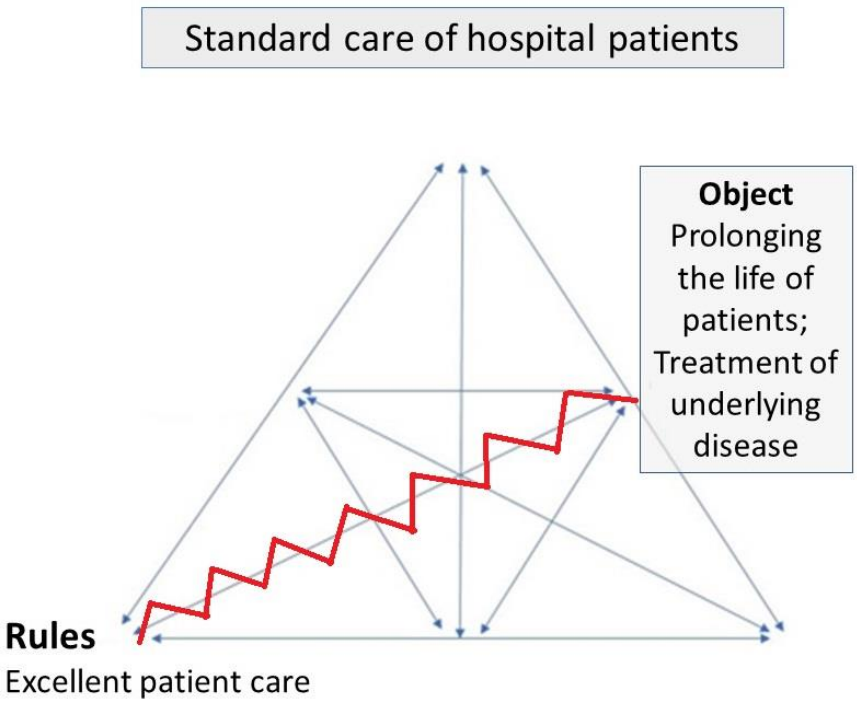


Figure 9 depicts a salient example of a secondary contradiction emerging in this ASA: the contradiction between the *rule* for patient to have excellent care and the *object* of providing life-prolonging treatments. The findings have indicated that default care in

the context of patients approaching the end-of-life is considered as poor care. CPR is an example of default care which is considered extremely unpleasant and invasive. Within this view of standard medical care activity, foundation doctors experience this contradiction.

Figure 10. Second example of secondary contradiction.

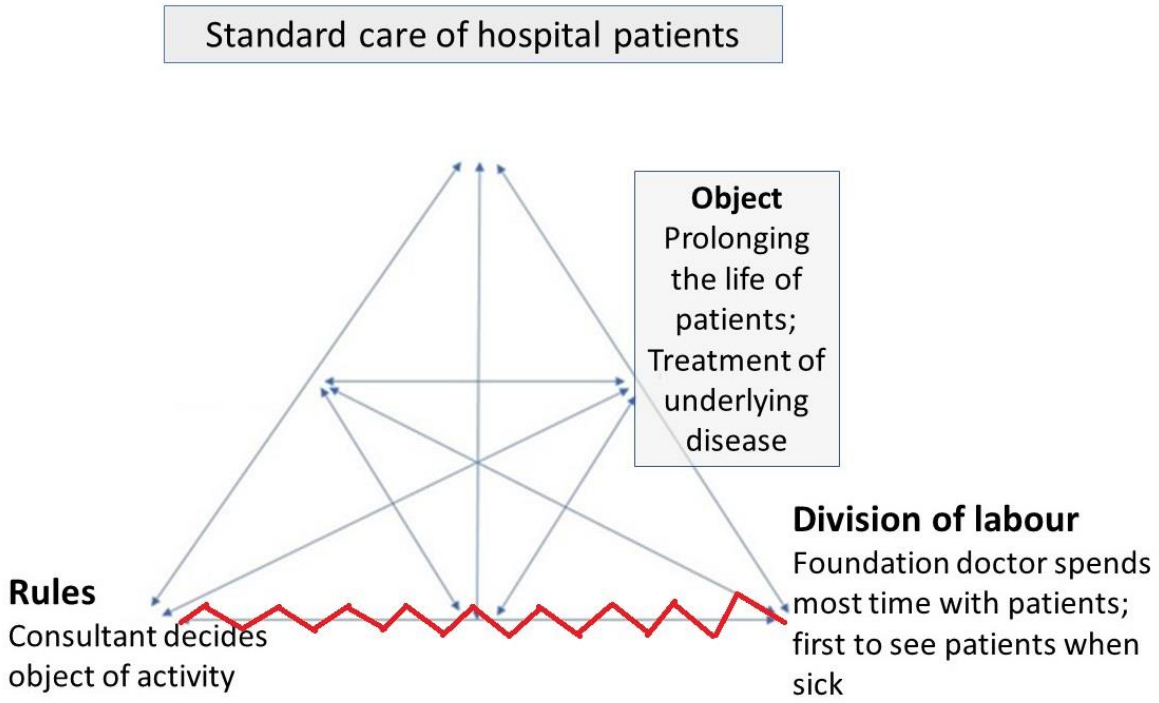


Figure 10 illustrates another salient secondary contradiction which can be conceptualised between *division of labour* involving foundation doctors often being the first to see sick and deteriorating patients and the *rule* of decisions about altering the object of care from. It is at such times that the foundation doctor may interact with their environment (such a perceived patient deterioration potentially acting as a *mediating artefact*) and come to understand that the patient is approaching the end-of-life. The foundation doctor may determine that the object of activity should change. When labour is distributed in such a way that senior doctors are not immediately

available, this may put the foundation doctor in a position where they need to break the rule by making decisions above their station (or of breaking the rule of providing excellent care, as above). There is further tension from the *division of labour* leading to foundation doctors spending more time with patients than consultants and often knowing them better. There is tension experienced between this and the rule of not being able to make decisions about the object of care.

6.4.3. Tertiary contradictions

> Camille: "You would write the notes as much as you could, 'this treatment direction isn't working, is there an alternative or should we be looking for an alternative', and sort of hope that this would be picked up on in the ward round the next day." *(FY2, 27 months since graduation)*

Tertiary contradictions occur when there is tension between the dominant version of an activity and a new version. The most prominent example of a tertiary contradiction which has emerged from analysis is that of the current organisation of the hospital compared to the older system (prior to MMC and EWTD). This is represented below in Figure 11.

Figure 11. Tertiary contradiction.

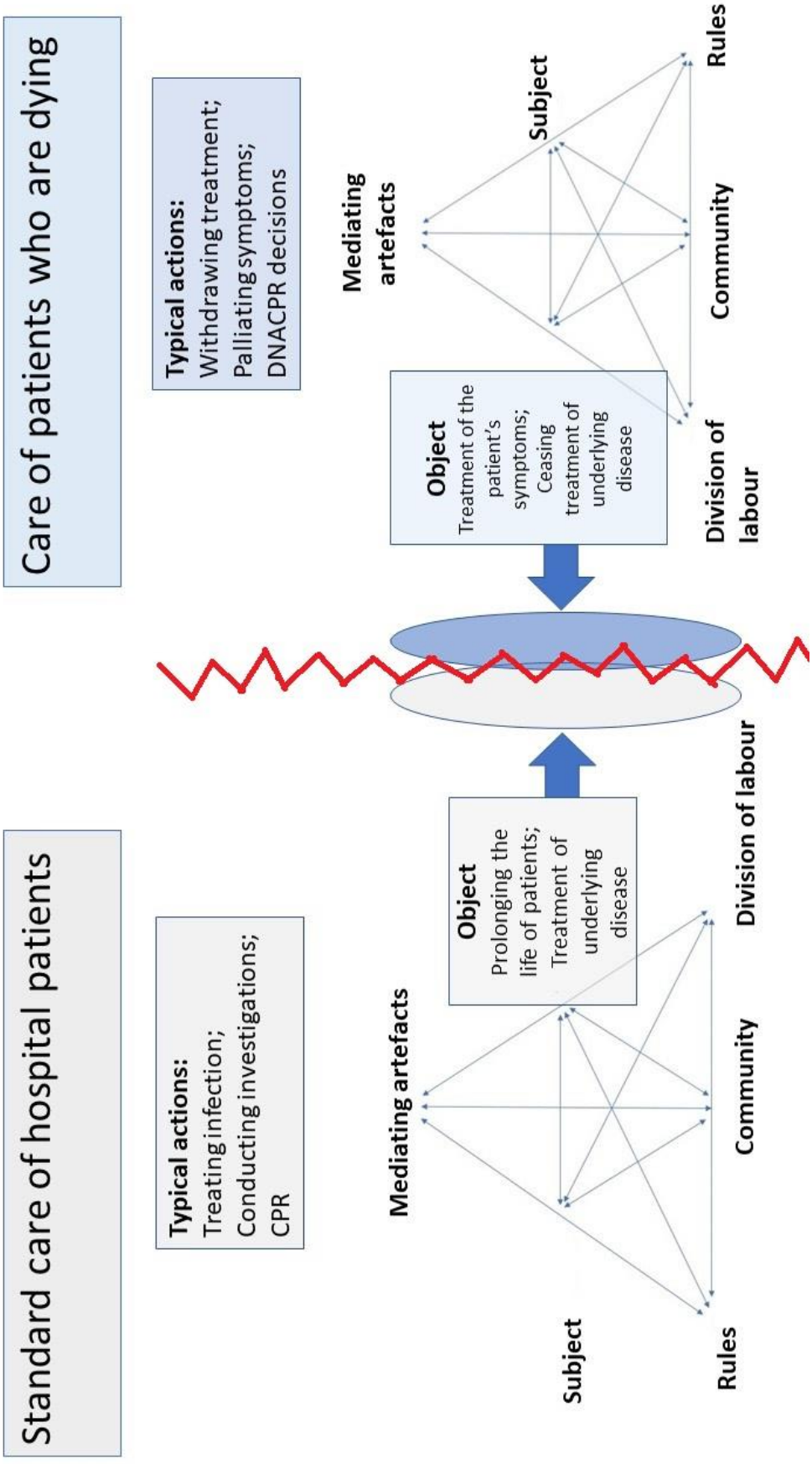
Existing knowledge of the patient and the consultant's plan is a mediating artefact in the practice of foundation doctors, facilitating understanding of the object of activity, and by extension, which activities are appropriate. Interacting with artefacts can therefore occur differently, depending on how labour is divided at different times of day. As described in Section 6.3.7, training changes resulting from MMC and EWTD have led to more disjointed working and shift systems. When working OOH, things may function as artefacts to mediate care of patients out with normal working hours, including what is documented in patient notes which can be read by different doctors later; handover between doctors working different shifts. However, these processes are not always successful and do not account for all possible eventualities the doctor will encounter. Although the newer form of activity has been devised with the intention of ensuring ongoing medical care for patients regardless of time of day, it can be seen that there is difficulty with this being attained in the same way as this the older version. This represents a contradiction between the older and newer versions of the system.

6.4.4. Quaternary contradictions

> Catriona: "There has been a few times where it's been overlapping, where you're actively treating, yet the person is on palliative care medication." *(FY1, 9 months since graduation)*

The major quaternary contradiction identified in this analysis is represented below in Figure 12, i.e. a contradiction between two or more activity systems.

Figure 12. Quaternary contradiction.



Certain treatments have ascribed cultural meanings associated with standard patient care, others with care for patients who are dying. This can be conceptualised as two different activity systems: standard patient care with the object of prolonging patient life; care of patients who are dying, with the object of treatment of patient's symptoms. From this viewpoint, artefacts mediate the foundation doctor in understanding the patient is approaching the end-of-life, i.e. there should be movement between the standard AS to the AS for dying patients.

However, it is not always clear to junior doctors what treatments are appropriate. Tension is experienced when they are required to carry out a combination of operations which do not clearly correspond with one AS or another. This makes it difficult for the foundation doctor to understand the overall object of care. Also, at times there may (atypically) be a return from the AS for care of dying patients back to standard patient care, which causes confusion.

Subjects also experience frustration when their interactions with mediating artefacts lead them to a conclusion that the object of care should change, but the activity system does not change. This can be conceptualised as a quaternary contradiction. Different activity systems have competing outcomes (Larson, et al., 2019), and in cases of quaternary contradictions, the foundation doctor feels there is an unsatisfactory outcome for the patient and doctor. In other words, foundation doctors are motivated to provide excellent care for their patients, but are frustrated when they are unable to do so because the objects of activity do not change when they come to understand the patient is approaching the end-of-life. Such unsatisfactory outcomes may include patients still receiving invasive treatments close to the end of their life, or the patient receiving futile attempts at CPR.

6.5. Building on the findings

6.5.1. Knowing-in-practice in activity systems

In this chapter, I have employed CHAT to theorise the activity of foundation doctors as part of collective activity. I drew upon the findings of the preceding studies which had demonstrated that the approach to the end-of-life is not a discrete biomedical entity but instead understood through practice and as related to elements of the practice of doctors. CHAT is a socio-material theory and a practice theory which matches well with this established idea of knowing-in-practice. I have gone further in this chapter, firstly by theorising about what the world must be like for certain phenomena to exist, and secondly by theorising about generative mechanisms at work, i.e. adding theory to the data (Edwards, et al., 2014b). This theorisation has taken a macroscopic view, considering learning of doctors in the workplace generally, rather than one locality.

Within organisations, systems exist which define the existence of communities of practice, their nature and their boundaries (Fuller et al., 2005). Based on the findings presented in Chapters 3 and 5, I theorised two separate objects which govern the activity of practitioners, which each have their own cultural expectations, and associated component actions and component operations. The standard default AS is that with the object of prolonging life. This contrasts with the care of the dying AS with the object of symptomatic relief. Within these systems, activity is mediated by psychological, tangible and intangible artefacts. These influence the doctor to understand what the object of patient care should be, and therefore which activity

(and which actions) are appropriate. CHAT can be used to theorise complex systems at different levels (Larson, et al., 2019). It has also allowed the work of junior doctors to be seen not only as occurring in one activity system but different systems. The approach to the end-of-life can therefore be theorised as the change from one activity system (AS) to the other (see Figure 7/Appendix 5).

As foundation doctors' understandings of their activity (and activities) increases (e.g. appreciation of significance of ongoing blood tests and interventions for patients), they notice flaws in accepted practice. This is necessary for expansive learning, which begins with the process of internalisation, whereby subjects move from abstract to concrete understandings. When subjects resolve contradictions, they develop means by which to improve activity and better achieve outcomes which align with their object (Engeström, 1987). I have argued that we can see that this externalisation occurs for foundation doctors learning to care for patients approaching the end-of-life. CHAT allows us to theorise about contradictions which emerge within and between activity systems, determining workplace factors which potentially require development or modification (resolution of contradictions) to lead to expansive transformation.

Contradictions were theorised at different levels within/between activity systems: primary contradictions, e.g. different valuations of input from nursing staff; secondary contradictions between, e.g. between division of labour results in junior doctors being called to see deteriorating patients they do not know, in tension with the artefact of pre-existing knowledge of the patient; tertiary contradictions between older organisation of the hospital system with the current form; quaternary contradictions between two different systems resulting in poorer outcomes for the patient. How these contradictions may be resolved are discussed in the next section.

6.5.2. Resolution of contradictions

Using CHAT, I determined workplace factors which potentially require development or modification (resolution of contradictions) to lead to expansive transformation. Expansive transformation occurs as part of the process of resolving contradictions, and so contradictions are part of an activity system's evolution (Engeström, 1987). If not learned from, contradictions within a system will tend to generate proliferation of further contradictions (Nunez, 2014). Expansive transformation can and should therefore lead to improved learning and practice for patients approaching the end-of-life. In this section, I will postulate about how resolving contradictions may be achieved. My postulations are in non-specific, general terms because, as I will go on to explain, I believe meaningful transformation needs to be driven by agents within the system, and therefore specific means of resolving contradictions should be defined and designed by the subject.

Boreham (2004) built on CHAT to propose *collective competence* as a response to the neo-liberal idea of workplace learning occurring as a result of individual performance at work. Boreham argued that competence can also be achieved as a team or community. This provides an appropriate framework for me now to postulate about overcoming the contradictions determined in this chapter.

Boreham argued for three inter-connected elements necessary to achieve collective competence within an AS. Firstly, he argued the system must demonstrate making *collective sense of events in the workplace*. The success of a community carrying out work depends on its approach to the object of their activity, but in order to make sense of events in the workplace there needs to be communication, and collective

interpretation of events encountered at work (Boreham, 2004). Contradictions related to the understanding of events can be seen at multiple points within the system, e.g. primary contradictions related to value of nursing input when nurses do not have a shared understanding with the doctor; quaternary contradictions when the foundation doctor struggles to reconcile actions associated with different objects of activity. This can be explained in CR terms as differences between empirical understandings which are always subjective and partial, not perceiving the entire event and certainly not perceiving all the generative mechanisms at work (see Figure 3, Chapter 2) (Bhaskar, 1975). As presented in Chapter 3, there are great disparities in the way the patient's approach to the end-of-life can be understood. There are multiple terms used by doctors to describe this area of patient care, but more fundamentally, there are no universal meanings of when a patient may be approaching the end-of-life. The approach to the end-of-life is a subjective, multi-faceted and patient-specific concept, therefore it is perhaps unrealistic to consider reducing it to a single term or sets of terms. Despite this lack of clarity, foundation doctors are not enabled to achieve the understandings they require, especially at times when labour division increases their autonomy (especially OOH work) and encounter difficulties in interacting with artefacts in useful ways (e.g. insufficient information in patient notes or handover; perceived rules preventing communication with consultants). Achieving collective sense of events may be facilitated by acknowledging the difficulty in determining the object and appropriate actions, acknowledging the uniqueness of each patient and their individual situation, and facilitating practitioners in interacting with mediating artefacts in a valuable and meaningful ways.

Next, Boreham argued that there should be *development and usage of collective knowledge base*: the use of shared work-specific language and ideas. This is challenging in the context of my research when there is no shared sense of events, and difficulties achieving mutual understandings. Collective knowledge has been achieved and endures, for example, in the context of the airline industry, where there is heedful inter-relating between practitioners in a specific way (Roberts and Weick, 1993). Roberts and Weick (1993) described a 'collective mind', constructed by airline practitioners giving conscious attention to the consequences of interactions between their actions and the environment. They attribute this to the very low rate of airline catastrophes to the collective mind. Within a healthcare context, the introduction of the surgical checklist (or surgical pause) is an example of developing and using collective knowledge heedfully (Treadwell, et al., 2014; Pucher et al., 2015). These checklists are enacted as communication processes designed to reduce surgical morbidity and mortality by intentionally facilitating every member of the operating theatre team to be conscious of each other, their actions and their environment. This may reduce errors because it reduces a sense of hierarchy and encourages all members of the team to speak out and catch near misses, and encourages anticipation of complications (Treadwell et al., 2014). This has parallels to the concept of distributed situational awareness: a conceptualisation of a distributed cognitive system where information flows iteratively between multiple practitioners and their environment (Fioratou et al., 2010). Overcoming deficits in collective knowledge in the systems under study could potentially be achieved by incorporating a method which encourages all members of the multi-disciplinary team to consciously consider their colleagues, their own actions and those of their colleagues, and

artefacts with which they interact for a patients on the ward receiving care, in a way comparable to the surgical checklist.

Lastly, Boreham argued that collective competence requires *development of a sense of interdependency*. Organisations contain sub-systems (Boreham and Morgan, 2004), and, as Engeström claimed, there is a potential source of conflict between professional groups in an activity system when they each have their own assumptions and cultural norms. Knot-working is an essential part of the functioning of an AS, and needs to be a deep and pervasive part of organisational culture (Engeström, 1987). What is valued and understood within one sub-system might not aligned with the goals of the rest of the group or the object of activity, leading to contradictions (Boreham, 2004). It is therefore vital to find ways to communicate and co-operate between sub-systems. Within the context of this thesis, this can be considered as the disparities in the sub-systems, for example, of nursing staff and doctors, or between senior doctors and junior doctors. This may be resolved through developing collective trust, and valuing and understanding the contribution of every team member. This is challenging in the context of the hospital where there is regular turn-over of staff, as junior doctors progress through their postgraduate training, involving rotation to different clinical departments. Even during one training placement there is relative lack of continuity, as a single placement can involve rotation between departments and variations in distribution of (e.g. being partially based on the medical receiving unit and partially based on a specialist medical in-patient ward). A further challenge to interdependency is the lack of awareness of the important role played by foundation doctors in care of the patient in the hospital. The lack of appreciation is perceived by both participants in my research, and more widely – exemplified in recent junior doctor strikes in UK (Goddard, 2016).

Boreham advised that interdependency can be overcome by acknowledging that divisions exist and deciding upon means to transcend cultural differences (Boreham, 2004). This could alternatively be explained as actors within an AS learning from and creating new knowledges through horizontal interaction[6] (Fuller et al., 2005). Boreham refers to recent trends across work organisations generally away from hierarchical and segmented cultures towards more flexible work in which all grades of employee are encouraged to engage in collaborative inquiry and continuous improvement (Boreham, 2004). To overcome contradictions through developing inter-dependency, all members of the healthcare team should be empowered to find means to improve their practice. This would also reduce alienation of foundation doctors who are instructed and expected to operate skilfully within a system which (so far) they have no control over (Fenwick, 2010b). Such a change may parallel with what critical realists call collective reflexivity: "a collectivity that evaluates objectives (discernment), deliberates about realizing its common concerns (deliberation) and commits itself to achieving them (dedication)" (Donati and Archer, 2015 p.62).

Engeström identified that dynamic research is required to progress, mediate, record and analyse cycles of expansive transformation. Engeström described seven typical steps in an expansive cycle:(Engeström, 1987)

- *Questioning* (criticisms or rejection of accepted practice);
- *Analysing* (finding out causes or explanatory mechanisms in a given situation);

[6] Within CHAT, division of labour is viewed as occurring horizontally while status and power are divided in a hierarchical or vertical way. Horizontal interaction refers to how workers collectively solve problems to create new knowledge (Fuller et al., 2005).

- *Modelling* (presenting a new model for activity in a publicly observable way);
- *Examining the model* (running or experimenting on the new model to ascertain its full dynamics);
- *Implementing the model*;
- *Reflecting* on and evaluating the process;
- *Consolidating* the outcomes into a new form of practice

Engeström (1987) claimed that small cycles of learning are more common, and that large-scale organisational change requires multiple small cycles of innovative learning. Engeström described formative interventions – those which focus on transformation and learning embedded in object-orientated activities. During formative interventions, contradictions are analysed in ways not known ahead of time, the contents of the intervention are negotiated and determined by the participants, new concepts are generated which may be used in other settings, and expansive transformation is provoked and sustained in a way which is led by the practitioners. Transformative agency occurs when there is breaking away from the accepted form of action, and subjects have agency to take the initiative to transform it. Agency of the participants is key to the process of transformative change, and CHAT can allow for analysis of how power and agency contribute to these changes (Larson, Nimmon and Varpio, 2019). One potential formative intervention is discussed as a potential area for future research in Chapter 7.

6.5.3. Future work: exploring activity of interacting professionals

The results of analysis and further theorisation presented in this chapter have indicated the great extent to which foundation doctors' practice-based learning occurs in interactions with human and non-human elements in their environment. In particular, the results show us how much they interact with other community members – senior doctors and nursing staff. Foundation doctors interact with the instructions and opinions of senior doctors, and input from nursing staff, in practice so these elements are culturally specific artefacts in their activity.

Different community members have different roles, different ways of speaking, dressing and behaving, and are likely to ascribe different cultural meanings to elements within their activity. Exploring the activities of these different professional groups would allow for further theorisation of how their systems interact with each other. Thus far I have collected insufficient information to comment fully on the activity of these other professional groups, and certainly not about their perceptions and how they make sense of artefacts in their environment. Exploring their practice (in a similar way as I have with foundation doctors) would be elucidating. This would include consideration of where tensions lie between interacting systems, i.e. quaternary contradictions

6.6. Advancing the thesis

This chapter has made a significant contribution to advancing this thesis. It built on the work of earlier chapters to incorporate CHAT as a framework for further

theorisation. CHAT has allowed: the practice of doctors to be considered within activity systems as units for analysis; discussion of systemic contradictions; representation of the findings of the analyses (Yamagata-Lynch, 2010). CHAT has been criticised as having little predictive power (Bakhurst, 2009), yet according to my ontological position, this thesis accepts that actors within the system may act in different ways at different times, and that research findings are not exactly reproducible. I have not argued that the activity systems I have developed can predict events, but they have provided a theoretical explanation of the learning and understandings of doctors at the approach to the end-of-life.

Within each AS represented, the dynamics are not apparent in their representation, but in the analysis and its use for reaching new solutions (Sannino, 2011). In this chapter, I have also postulated about how solutions may be reached (Section 6.5.2). Resolution of contradictions should promote transformative agency of the foundation doctor and reduce sense of the alienation within the system. Incorporating CHAT has also provided consideration of necessary future research: investigating the activity of other MDT members, and consideration of how contradictions between activity systems affect care of the patient approaching the end-of-life.

6.7. Conclusions

This thesis aims to develop an explanation of how medical doctors learn about and understand patients approaching the end-of-life. To achieve this, it has been necessary to investigate how the approach to the end-of-life is conceptualised and understood among medical doctors, and to explore how the approach to the end-of-

life is experienced by doctors learning in the workplace (presented in Chapters 3 and 5). In this chapter, I have drawn on these results using CHAT as a framework to develop a theoretical explanation of the learning of doctors about the approach to the end-of-life. Through this, I have argued that doctors understand and know about the approach to the end-of-life through practice, mediated through interactions with social others, and culturally specific artefacts. This theorisation is not only one of academic interest: it has allowed me to consider where barriers to practice and learning are encountered, and to postulate means by which learning about the approach to the end-of-life can be facilitated and improved. In the next chapter, I will summarise and argue that my work in this thesis has addressed my aim and present a discussion for the implications of this thesis for research and practice.

7. Discussion

7.1. Introduction

The overall aim of this thesis is to develop an explanation of how medical doctors learn about and understand patients approaching the end-of-life. The individual pieces of work presented have each contributed to achieving of this aim. Within each of the chapters which contributed new findings (Chapters 3, 5 and 6) I presented a discussion of the significance of the findings of individual studies and contextualised them in the existing literature. This chapter now aims to consolidate the findings of my research, present an integrated argument about the learning of medical doctors understanding patients approaching the end-of-life, and discuss the implications.

I will begin by summarising the key findings from my research and analysis. I will then discuss the implications of these findings to practice, how practice may be changed, and where challenges to change are likely to lie. I will discuss issues of trustworthiness in the construction of this thesis, and then discuss where the thesis is limited. I will discuss the findings in the context of existing literature, clearly explaining the contributions I have made. Lastly, I will postulate and recommend the next stages of research and development to usefully build on this work.

7.2. Summary of thesis arguments

This thesis has an underpinning ontological perspective aligned to critical realism (CR): holding that events that occur in the world (which individuals may or may not perceive) come about through multiple interacting generative mechanisms (which exist regardless of human perception of them, regardless of whether events occur). CR supports epistemological flexibility in order to investigate and theorise about external influences, seeking to gain the truest picture of mechanisms which lead to material events, accepting that empirical experience is inevitably fallible (Bhaskar, 1975) (see Figure 3, Chapter 2). In order to investigate the influences on the learning, I adopted a socio-material epistemological perspective which considers knowledge as produced and reproduced socially and in interaction between human bodies and materials (Fenwick, 2010a; Zukas and Kilminster, 2014). This corresponds with a practice-based viewpoint, i.e. a conception of knowing-in-practice rather than knowing-for-practice (Gheradi, 2012).

In Chapter 3, I presented an investigation of how the approach to the end-of-life is understood by medical doctors. I performed a comprehensive scoping study in order to obtain a significant breadth of UK medical literature. Qualitative Content Analysis generated different conceptions of the approach to the end-of-life with meanings ascribed to the patient and actions of doctors. Thirteen conceptions were categorised as related to how the medical literature discussed conceptions of the 'patient and illness' from the doctor's perspective. These do not conceive the approach to the end-of-life as static, and do not rely purely on biomedical factors. Instead these incorporate dynamic social and historical considerations. Seventeen conceptions were categorised as referring to the 'care of the patient': the approach to the end-of-

life was linked to the care available or being administered and/or the actions of doctors and other healthcare professionals. Certain concepts within this category were considered to relate to harmful, damaging or otherwise negative care when the patient is approaching the end-of-life, while others were discussed positively. This allowed for an understanding that default medical care is not designed for patients approaching the end-of-life and that curative or life-prolonging intent was conceived negatively for the patient approaching the end-of-life. For such patients, other care – which was not default or standard – was considered positively.

I argued that the approach to the end-of-life is not uniformly defined and not conceptualised as a discrete entity. There are parallels between the way the approach to the end-of-life is conceptualised by medical doctors and existing literature discussing the social constructions of illness (Conrad and Barker, 2010) and death and dying (van Brussel, 2014). My findings indicate understandings of the approach to the end-of-life are not biologically essentialist; instead they can be seen to be socio-materially constructed, incorporating judgements from the viewpoint of the practicing doctor, and also the materials and means which are available and possible for the practising doctor.

Chapter 5 presented findings from my primary data collection and analysis of semi-structured interviews with doctors, exploring how the participants perceived and experienced patients approaching the end-of-life. Data were generated from newly graduated doctors, i.e. foundation doctors, who had recently moved from medical school and begun work, in order to investigate the influences of entering the workplace on practice and learning. Inductive thematic analysis generated five major themes: *Perceptions of patient care; Understanding the approach to end-of-life; Role of the doctor; Preparation for the role; Influences on workplace learning*. The findings

indicate foundation doctors perceive that hospitals provide life-prolonging treatments by default. After beginning practice, foundation doctors deepen their understanding of the system in which they work and develop opinions about when patient care should change from standard care to receiving different types of care when patients are approaching the end-of-life, although effecting such changes is challenging. Foundation doctors perceive that the need for this change should be recognised, including considerations of the patient and the implications of treatment.

However, as juniors, foundation doctors ostensibly have relatively low levels of responsibility and act under the supervision and/or instruction of senior doctors. Specifically, foundation doctors do not have responsibility for altering the goal, and yet are responsible for patient care – they are often the first doctors to assess sick and deteriorating patients. Different members of the multi-disciplinary team play different roles and interact with each other in practice. The role of the foundation doctor and level of autonomy afforded to her/him is based on organisational and systems-based needs rather than learner-centred reasons. The learning and practice of the foundation doctor in conducting practice in patient care is influenced by various workplace factors, which also contribute to their understandings of when a patient is approaching the end-of-life (influence of nursing staff; organisational factors; time and experience; emotional reactions).

The findings correspond with the view of medical doctors understanding the patients' approach to the end-of-life through their practice after taking up the role of the doctor, i.e. knowing-in-practice. In Chapter 6, in order to further theorise about the systems-based influences on this practice, I applied a socio-material theory and practice theory: Cultural-Historical Activity Theory (CHAT). Using CHAT, I drew upon the findings presented in Chapters 3 and 5. I theorised two separate objects of care: one

of prolonging life associated with certain actions, e.g. ongoing treatment of cancer; one of symptomatic care only associated with different actions, e.g. withholding or withdrawing certain treatments. The objects are associated with two separate interacting activity systems (standard care and care of the dying patient) in which the foundation doctor is the subject whose activity is mediated by psychological, tangible and intangible artefacts.

The approach to the end-of-life can therefore be theorised as the change from one activity system (AS) to the other. Subjects interact with artefacts which mediate their understandings and can facilitate the object of activity changing (see Figure 7, Chapter 6 / Appendix 5). Tensions are experienced (contradictions in and between the activity systems) at different levels within the system: primary contradictions when there are contradictions in exchange and use value of component elements within of the AS (e.g. input from nursing staff); secondary contradictions between different elements of an AS (e.g. division of labour results in junior doctors being called to see deteriorating patients they do not know, in tension with the artefact of pre-existing knowledge of the patient); tertiary contradictions between new and older forms of activity (contradiction between the older organisation of the hospital system with the current form); quaternary contradictions between two different AS – the tension between the two theorised AS resulting in poorer outcomes for the patient. The implications of these findings for practice and education are considered in detail in the next section.

7.3. Implications for knowing-in-practice

The key research findings confirm the view of learning as occurring in practice, i.e. knowing-in-practice. In this section I will consider how these key messages from the findings represent challenges in practice, how practice may and/or should change in response, and what challenges to these changes may exist.

7.3.1. Challenges to practice

End-of-life care is a vitally important aspect of patient care and providing excellent end-of-life care is the responsibility of healthcare services (Parlimentary and Health Service Ombudsman, 2014; NICE, 2015). I have argued this must be seen to include understanding the approach to the end-of-life (Chapter 1). My findings allow for consideration of how doctors develop this understanding through practice and how their ongoing practice affects their understandings for the individual patient in dynamic ways. Differences exist between practitioners in determining when the patient is approaching the end-of-life and when it is appropriate to stop life-prolonging treatments. Confusion among the public has been noted previously about the significance of end-of-life care (McIlfatrick et al., 2013). However, the challenges indicate lack of clarity for doctors as well as for patients and lay people, which represents a challenge for practice (and learning to practice) in this area.

The findings also indicate the vital role played by foundation doctors in patient care. Although previous research has identified the important role junior doctors play in end-of-life care, and the challenges they face at these times (Gibbins et al., 2010;

Murray-Brown, et al., 2015; Price and Schofield, 2015), my research has gone further to centre the foundation doctor in the care of patients at the *approach* to the end-of-life. This aligns with the knowledge that foundation doctors are caring for the sickest patients, and so will be involved in their care at times when the object of their care changes. The apparent lack of acknowledgement of the foundation doctor, not as peripheral participants, but as central to these processes correlates with a lack of understanding among the general public of the vital role played by junior doctors in care of acutely sick patients (BBC News, 2016; Clarke, 2017).

Instances where patient care has not changed appropriately to reflect that the patient is approaching the end-of-life are acknowledged as contributing to patient harms (Parlimentary and Health Service Ombudsman, 2014). For foundation doctors, enacting care of the patient approaching the end-of-life is mediated and often challenged by several factors encountered in the workplace (see Chapters 5 and 6). The literature indicates continuing treatment with life-prolonging intent is perceived negatively by doctors; foundation doctors perceive poor patient care when they are compelled to provide care they feel is inappropriate for the patient approaching the end-of-life (perceived as *invasive, aggressive*). Analysis of the medical literature has indicated that standard healthcare is designed to facilitate life-prolonging treatment. The idea that the healthcare system is designed to provide cure or life-prolonging treatment, and that patient deaths are a failure is reflected in discourse which measures the quality of patient care in terms of mortality (Lilford et al., 2004; Lilford, 2010).

Providing improved patient care for patients approaching the end-of-life is unlikely to be achieved by attempting to reach a single objective understanding of what

constitutes this for every patient in every context. It will also not be achieved (simply) by improving what is learned about *in advance* of practice. Instead, improvement may be brought about by facilitating a system that can appropriately allow the object of care to change when a patient is approaching the end-of-life, without patient care being impeded by barriers to this change. My findings emphasise the perceived importance of this change in object only occurring under appropriate, considered circumstance, and allow for change back away from this object should circumstances change.

In other words, if our goal is to provide excellent end-of-life care to patients, the system of the hospital should allow the object of care to change for patients when appropriate, and a key aspect should involve accepting the important role of foundation doctors and altering the system in order to facilitate them doing their job. The potential for change in practice is discussed in detail below.

7.3.2. Changing practice

This research has been conducted with the wider backdrop of major upheaval in the working lives in junior doctors. Although recent junior doctor contract changes do not so far affect the Scottish NHS, there was sensitivity to these issues among junior doctors working in Scotland (Wilson, 2015). Lack of appreciation of and dissatisfaction among junior doctors has been reported (Lamb, 2017; Smith et al., 2018). This culminated in junior doctor strikes in England, as junior doctors felt that their concerns about patient safety (and how the distribution of their workload affected patient safety) had not been listened to. Policy makers proceeded in making changes

which affected the working lives of junior doctors despite the major concerns raised (BMA, 2016b). This represents junior doctors being instructed to operate in a system over which they have no control – in Marxist terms, the worker being alienated from their product (Marx, 2013). There is ongoing public discourse about difficulties faced by junior doctors (e.g. Campbell, 2019). These indicate a wider context of junior doctors struggling to obtain agency in their own work.

In the context of my research findings, junior doctors (specifically, foundation doctors) experience challenges in a wider organisational system which they do not control. When foundation doctors transition into practice they become immersed in the working world and become familiar with norms of the culture, understand how elements are connected, and appreciate the wider significance of different actions (*internalisation* in CHAT terms). As they continue to practice, they begin to inwardly question the processes in which they work (*externalisation*) and are aware of challenges to their practice (*contradictions*). However, although foundation doctors have responsibility, they are not afforded authority to determine systems factors which affect their own work. Foundation doctors are motivated to provide good clinical care, and effecting treatments, including those with which they disagree, are perceived especially negatively if they lead to poor patient outcomes. If practice is to change, it is important that is done in a way which is good for doctors and safe for patients. Based on my findings – and the wider cultural context – I suggest that by listening to and incorporating the ideas of doctors, policy makers may be better able to align the organisation of hospital systems with the objective of providing excellent patient care. Facilitating junior doctors in their practice is likely to have benefits to patient care.

In Chapter 6, I utilised Boreham's (2004) CHAT-derived theory of collective competence to theorise about how challenges to practice can be improved through *making collective sense of events in the workplace*, *development and usage of collective knowledge base,* and *developing a sense of inter-dependency.* Although achieving increased collective competence according to these domains may have been achieved in another area of healthcare practice – the surgical checklist (Treadwell, Lucas and Tsou, 2014) – it appears not to have been achieved in care of patients approaching the end-of-life. According to Engeström's idea of expansive learning (or expansive transformation) resolution of contradictions within a system may be achieved through transformative agency: moving away from accepted practice to transform practice into something new. This relies on subjects within the system having agency to transform it (Engeström, 1987).

Building on these ideas, increasing awareness, respect and inter-working between practitioners (akin to increased cultural competence) could facilitate greater agency of subjects and therefore contribute to expansive transformation. That is to say, improved practice could be brought about by reducing hierarchical and communication barriers, and acknowledging the important roles of every member of the working community, including foundation doctors. Presently, foundation doctors experience hierarchy in their role and are limited in their ability to determine their own actions and, to varying extents, being able to outwardly question or criticise practice. However, my findings indicate that the capacity for junior doctors to question the rationale of instructions is especially pertinent in this area of practice: there are disparities in understandings of the approach to the end-of-life among doctors including when and how it occurs, what it constitutes, and where its limits lie. The approach to the end-of-life is subjective and often situation-specific. One should not

assume that understandings are shared between practitioners. Furthermore, as foundation doctors spend more time with patients than more senior grades of doctors, the consultant should not assume that their understandings of the correct object of care for the patient is as well-informed as the foundation doctor's.

I have not discussed the specific formative interventions to overcome contradictions or the specific future iterations of workplace organisation, because I believe these should be determined by the subjects in the system, acting as agents of change (although I make suggestions for future research and development later in this chapter). Below, I consider the challenges which may exist to change in this area of practice.

7.3.3. Challenges to change

Thus far I have discussed the possibility of the hospital workplace changing in ways that more easily facilitate the care for patients approaching the end-of-life. Within healthcare there are established cultural beliefs of death as a failure, which may make doctors reluctant to accept that a patient is dying (Christakis and Lamont, 2000; Kennedy et al., 2014). My findings indicate this is represented in both medical literature and the empirical experiences of foundation doctors: the default position for doctors is that healthcare should prolong life and deviations from this are non-standard and difficult to effect. This is despite doctors considering continuing interventions with life-prolonging intent until close to the time of death dissatisfying and upsetting (see Chapter 5 and Donnelly and Dickson, 2013; Taylor, 2014). There

is an identified need for palliative care research to inform policy in order to improve patient care (Finucane et al., 2017).

Furthermore, death rates are used commonly as a measure of the quality of health services. For example, a report by the Department of Health outlined a disproportionate number of patient deaths that occur OOH within the NHS and represented this as poor care, although this report has been criticised for providing a biased impression to the public (Rimmer and Kmietowicz, 2015). Although standardised mortality ratios have been used to demonstrate failures in healthcare provision (e.g. the Mid Staffordshire NHS trust) their use has also been criticised as providing an unhelpful, misleading and simplistic view of healthcare – i.e. the death of a patient does not necessarily mean that care was inadequate (Lilford, 2010). The use of death rates in this way is a further demonstration of a deep-rooted perception that patient death is a failure.

The view of the purpose of healthcare is to prolong life is not only held among doctors, but among the general public as well. In modern British society, laypeople do not see dying in their everyday life. The need for a wider general awareness and discussion of the inevitability of death among the public has been identified (Seymour et al., 2010). Vast improvements in modern healthcare mean that people are living longer with chronic conditions and have high expectations that medicine will allow a person's life to be extended (Littlewood, 1993). This may perpetuate the view among patients and public that when a doctor cannot do this, it is as a result of their failure. Patients, and their relatives, who hold this view can put pressure on doctors to continue treatments with life-prolonging intent even when the doctor's understanding is that the patient is dying (Greene, 2013).

Such attitudes have been represented in certain well publicised cases where there was disagreement between patients/carers/the public and the judgement of doctors regarding the goals of treatment (Hammond-Browning, 2017). For example, in the case of Alfie Evans – an infant born with a neurodegenerative disease – there was disagreement between the patient's parents and doctors about whether invasive ventilation should be withdrawn. Although the doctors' understanding was that it was futile and therefore not in the patient's best interests to continue treatment with life-prolonging intent, the parents wished for this to continue. The public controversy surrounding this indicated a perception that doctors were inappropriately and unethically altering the goal of the patient's care, and therefore should be held responsible for the patient's death (BBC News, 2018). This was a particularly controversial case, however it is indicative of barriers to understanding the patient approaching the end-of-life which may exist among the general public. Such an attitude may extend to patients with diseases that will inevitably lead to death (McHugh et al., 2015).

I have also suggested that changes to practice incorporate empowering the junior doctor in the workplace system to question and criticise current iterations of practice and be agents for change. Junior doctors are practitioners motivated to provide a high standard of patient care but operate under the constraints and influenced by organisational factors. This stands in contrast to much literature which discusses the importance of individual resilience in medical education (Cooke, Doust and Steele, 2013; Wood, 2016). It also stands in contrast to putting individual blame on practitioners for poor or suboptimal patient care. In the well-publicised case of Dr Bawa-Garba, for example, there was criticism that this doctor was judged harshly and was apparently receiving sole blame for mistakes, even though she was one

practitioner operating within a wider system, and under the influences of workplace factors within that system (Clarke, 2018). The implications of my findings are that discourses of preparation for practice, of individual resilience, and of individual blame are perhaps inappropriate and unhelpful. For the sake of patients and doctors, organisations should consider how they can better facilitate the learning and practice of their postgraduate trainees, and move the onus of responsibility away from medical schools and the individual practitioner.

There are likely to be several cultural barriers to such a change in workplace systems. Organisational factors which prevent health practitioners from speaking up about concerns related to patient care exist including power differentials between team members, risks of psychological damage and a seemingly pervasive culture of silence (Rowland, 2017). Traditionally, medical training occurs within a structured hierarchical culture in which doctors have been socialised. This establishes the junior doctor as weak in comparison to senior doctors (Crowe, et al., 2017). This is represented in my findings, which indicate that foundation doctors have perceived responsibility but relatively little authority. The consultant is assumed to inherently know the best correct course of action, and for the junior doctor to contradict this goes against the norms of the system. For example, it is nurses and foundation doctors who carry out CPR in cases of cardiac arrest, which is experienced very negatively when it is unsuccessful, although it is consultants who make decisions about DNACPR. Interestingly nurses – who have lower perceived power than doctors – tend to approach foundation doctors in preference to consultants with their input.

In contrast to existing cultural norms, developing a sense of inter-dependency by actively appreciating and involving every member of the multi-disciplinary team, including junior doctors, will involve acknowledgement of the important work done by

all members. It will allow junior doctors to be agents for change their own workplace and potentially reduce the perceived power differential between these two groups. Such a cultural shift may involve consultants – who have ultimate responsibility – taking on different leadership styles. Leadership styles may be categorised as existing across a spectrum of autocratic to democratic, or as relationally-focused to task-focused. Transformational leadership is a relationally-focused form which involves having awareness and clarity of different roles played by team members, and influencing, inspiring, motivating and intellectually stimulating individuals to achieve results and reduce conflicts (Cummings et al., 2010; Vaismoradi et al., 2016). A shift to a transformative approach to leadership may be needed, as opposed to more authoritarian forms. Changing the established educational and leadership practice of consultants in Scotland – who already have little educational training despite their responsibility for learners (Schofield et al., 2009) – is likely to be challenging.

Furthermore, there are organisational barriers to foundation doctors becoming active agents in expansive transformation. Expansive transformation takes time for development of new models of activity, repeated iterations and evaluation of results (Engeström, 1987). By the nature of the highly prescriptive and inflexible system in which foundation doctors work and train, they have limited time in one department, and even within one hospital. As has been discussed even in the space of one training job, the division of their labour may mean they are not physically located in one ward and may not have one pattern of working for longer than a few days at a time (see Chapter 6). Furthermore, junior doctors have other responsibilities despite the day-to-day completion of their clinical duties including obtaining post-graduate training competencies, completion of postgraduate examinations, maintaining

portfolios, preparation for admission to future training programmes, and completion of clinical audits and quality improvement projects (NHS Scotland Deanery, 2016; Healthcare Quality Improvement Partnership, 2016). This distribution of work and the demands on work are likely to provide barriers to junior doctors becoming integrally involved in change. It can be argued that such a work structure limits the capacity for junior doctors to have any meaningful input into changing their system by design.

The General Medical Council (GMC) commissioned a review of postgraduate medical training (Greenway, 2013) and has subsequently planned for changes to the structure of training programmes in the UK. This sought to create a new training system which addresses some of the difficulties of the inflexibility of training as well as provide for more generalist basis for training (GMC, 2019). Additionally, following the controversy surrounding the junior doctor's strike, NHS Health Education England has commissioned a working group focused on 'enhancing junior doctors working lives'. This aims to find solutions to common complaints of junior doctors including lack of flexibility of training and being allocated to training locations which are far from their home (Health Education England, 2018). The effects of these interventions on the future experiences of junior doctors in training remain to be seen. However, it is noteworthy that neither of these reviews of the working experiences of junior doctors, with resulting subsequent changes for this group, were led by junior doctors.

I have argued that fostering a system which will be open to change in its approach to care of patients approaching the end-of-life and facilitating junior doctors as agents for this transformation could lead to improved practice. For the workplace to be so open to change – and then subsequently to actually change – it would need to overcome cultural challenges related to medical and lay assumptions about the

purpose of healthcare, hierarchical power differentials within medical education, and organisational challenges which limit the ability of junior doctors to participate in expansive transformation. This thesis presents an argument for the value in proceeding to find ways to mitigate these challenges. Means of overcoming these challenges may need to be considered in any expansive learning model as an integral step in achieving transformed practice. Later in this chapter, I will also present recommendations for future research and development, to gain a deeper understanding, obtain new insights, and gather a broader research base to strengthen the drive for change.

7.4. Limitations

It is important to be cognisant of the limitations of this thesis. Throughout this thesis I have highlighted limitations in the methodologies and analyses at appropriate points in individual chapters. This section will discuss the limitations of the entire thesis, and what limits the certainty of my claims. Research findings in this thesis have been generated through analysis of medical literature and primary data generation through individual semi-structured interviews. It has allowed theorisation of mechanisms and processes at work which influence the learning of doctors in practice. However, there are undoubtedly further generative mechanisms which have not been considered in this thesis. Much of the potential limitations discussed here relate to mechanisms which have not been elucidated, or other perspectives which have not been taken, in this research, as will be discussed.

7.4.1. Observing practice

Researchers who incorporate CHAT in their work often also carry out observations (Yamaga-Lynch, 2010). Observations can complement other methods by allowing direct data generation about what practitioners do and say in their natural environment (Robson and McCartan, 2016). However, my empirical data generation has relied on participants' own accounts of their practice and experiences, and no observations were conducted. From a CR standpoint, subjective individuals are never able to perceive a complete picture of events, and events – and generative mechanisms – exist regardless of whether they are perceived (Bhaskar, 1975). If I was to conduct observations of participants I do not believe the data I generated would have been objective, nor would I have been able to perceive a complete picture of what is real, but could have generated further insights which did not come about from the individual interviews.

In this thesis I have considered the activity of doctors working across the entire general hospital organisation as opposed to focusing on one sub-group of that organisation. This contrasts with a more microscopic study design such as focusing on how practitioners within one department in one hospital interact with one another and how this affects learning and practice. Such a study may have incorporated interviews with different practitioners, for example, in a single ward, and also carrying out observations in that setting over a period of time. Another possibility would be to longitudinally collect data from a group of foundation doctors from the point of graduation throughout the programme, incorporating observations of their practice and longitudinal diaries in order to investigate their learning in practice.

The approach I have taken was appropriate as it allowed me to consider the general hospital as an over-arching entity. However, different and/or more specific insights may have been gained through incorporation of observations in this research. Now having developed this thesis, future research should build on this by investigating what can be gained from observing learning within a specific site. This is considered in future research later in this chapter.

7.4.2. Wider cultural influences

In this thesis, I have considered how workplace influences mediate the learning and practice of doctors in the care of patients approaching the end-of-life. When learning in the workplace, there is engagement in an activity which is defined by the negotiation of meanings both inside and outside the community (Fuller et al., 2005). In understanding the approach to the end-of-life, there are likely to be influences on this subjects which have not been elicited during this research. This relates to the concept of the organisational field: the notion that the actors in individual organisations are mediated by wider cultural and social structures (Wooten and Hoffman, 2001).

I have discussed the significant cultural and social background in which my research is grounded (Chapters 1 and 6). However, I have not carried out an investigation of how cultural influences outside the workplace influence individuals. It may have been fruitful to consider how experiences and influences outside of the workplace or medical training influence opinions and actions of doctors when the patient is approaching the end-of-life. However, this research has been grounded in practice

studies and I have argued for its relevance to practice and medical training. I have not made novel claims about relevance to wider culture and so do not believe this thesis is substantially undermined by the lack of this investigation.

7.4.3. Remembering the individual

This thesis could potentially be criticised for its consideration of structural factors over individual agency to explain individual behaviour. The favouring of structure in the structure-agency debate – i.e. explaining individual behaviours only as results of process – is of particular concern among critical realists such as Archer (2003), who disavows the under-theorisation of the individual within social research. Workplace learning theories differ in how they incorporate the role of individual agency (Sukhera et al., 2018). CHAT has faced the criticism of privileging the social over the individual. Critics have stated that CHAT only considers learning as part of group practice, and ignores the presence of individual learning and reflexivity (Wheelahan, 2004).

CR scholars hold that humans in the social world are held to be different from animals in the natural world due to agency. Human agents do not only react passively to the "pushes and pulls" they encounter but act reflexively and have active agency, derived by their ability to consider what they care about most. Although traditionally under-valued by social theorists, Archer argued that human reflexivity depends on the ability of humans to be able to hold internal conversations, i.e. talk to oneself in one's own head. Humans encounter events involuntarily, and *internal conversation* occurs in relation the human's own concerns, which determines their course of action.

Reflexivity is indispensable to society, but some forms of social organisation foster greater reflexivity than others (Archer, 2007).

I have aimed to balance representing both collective and individual learning in this research by use of one-on-one interviews with foundation doctors which explored individual perceptions, and theorisation about the results using CHAT.

It is also important that the individual is not privileged disproportionately as the power in an activity system is with the experts (in the context of this thesis, consultant doctors) (Wheelahan, 2004). Novices are vulnerable and disempowered but may develop power and agency as they may learn within an activity system (Engeström, 1987). In my research, I have represented the importance of the individual by elucidating that the foundation doctor does begin to question the structures within their environment as they are internalised within it. However, it may have been fruitful to complement the existing research by generating data which reflects the internal conversations which are held by foundation doctors in their practice of care of patients approaching the end-of-life. In CHAT terms, this would reflect the details of how subjects' internal conversations occur when they interact with artefacts in their environment, i.e. how this contributes to meditation. This may have taken the form of asking foundation doctors to record reflective diaries about their thought processes as they progressed with their training over time (Lundin et al., 2017). Although this may have provided new insights, I do not believe its absence has undermined my argument: for expansive transformation to be achieved, foundation doctors must have greater power as individual agents within their system.

7.4.4. Medical school perspective

This thesis has been grounded in studying workplace learning. I have argued that learning to care for patients approaching the end-of-life occurs in the workplace. In the UK, medial schools do not adopt an apprenticeship model as they may do in other settings (Dornan, 2012), and so I have not considered the medical student as fully immersed in workplace learning. In care of the dying, there are particular barriers to medical students gaining appropriate experience (Gibbins et al., 2011). This is reflected in my findings, that the approach to the end-of-life is not understood at a medical school level but begins after starting work as a doctor. Even when there is exposure to patients already accepted to be dying, this does not involve medical students in the processes involved in the patient's object of care changing from life-prolonging intent to treatment of symptoms (see Chapter 5).

CHAT is not a tool for analysis of the psychology of individuals and has been criticised as such (Yamagata-Lynch, 2010). There are other medical education researchers who adopt more cognitive perspectives to learning – assuming knowledge as being disconnected from bodies and materials. In the context of this research, this may have been involved detailed consideration of clinical decision-making and/or clinical reasoning processes (e.g. Peters et al., 2017) at times when a patient is approaching the end-of-life. Had this research taken such a perspective, one might argue it may have led to generation of 'knowledges' which could be 'learned' from an acquisitional viewpoint (Zukas and Kilminster, 2014).

However, I have taken a view of knowledge as existing in-practice rather for-practice (or in advance of practice) and so have not situated the findings in the context of

medical schools. This perhaps limits the usefulness of this thesis to undergraduate training, however it is important that medical students learn about end-of-life care (Linklater et al., 2014). Although my findings demonstrate that the approach to the end-of-life is a complex and uncertain area of practice, medical schools are responsible for preparing medical students for practice as doctors including situations of complex clinical situations and decision making in uncertainty (GMC, 2015). National and international recommendations of palliative care competencies for medical school curricula have been established. These highlight the importance of medical students learning about disease trajectories (one conceptualisation of the approach to the end-of-life) (see Chapter 3) and generally discuss the importance of learning about end-of-life care (Gamondi et al., 2013; Linklater, et al., 2014). More recently Boland et al (2019) have highlighted the importance of ensuring teaching about palliative care should be integrated across specialties and curricula, and include exposing medical students to dying patients, which may allow them to gain understandings of times when the object of patient care changes. Nevertheless, based on my findings, I suggest that unless medical students are integrated into the workplace in the same way as junior doctors, they are unlikely to gain a practice-based understanding of the approach to the end-of-life.

7.4.5. Patient perspectives

A further potential criticism of this thesis is its doctor-centred consideration of the approach to the end-of-life. I did not predetermine that consideration of the patient perspective should not be included in this research. In my inductive research

(Chapters 3 and 5) I established that doctors were influenced by their knowledge of the patient, which included their knowledge of the patient and their judgements (from a doctor's perspective) of the patient's quality of life. However, incorporating patient understandings or communication with patients has not been found to be a major influence. Furthermore, the approach to the end-of-life has been conceptualised as occurring after processes and decisions made by doctors, not by patients. Consequently, the individual patient is not theorised as being a clear element of the resulting activity systems (Chapter 6).

The motivation of the doctor should be to provide care which meets the needs of patients. The importance of aiming to align actions with patient wishes is recognised as good practice in palliative and end-of-life care (Brighton and Bristowe, 2016). Patients do not necessarily share understandings with doctors, which may affect their preferences and choices (Nickel et al., 2017). Although this thesis has fulfilled its aim in exploring the learning of doctors, it would be useful to practice for further research to consider patient understandings and perspectives of the approach to the end-of-life. This knowledge should inform the practice of doctors and the wider hospital system. This is discussed later in the chapter as an area for future research.

7.5. Contribution to existing literature

Throughout this thesis, in each chapter I have situated my individual findings and theorisation in the context of existing literature. As an entire body of work, this thesis can now be viewed as meaningfully building upon and connecting literature across different domains: determining understandings of concepts related to end-of-life care;

junior doctors learning to provide end-of-life care; workplace and practice-based learning.

Previous authors have noted the lack of uniformity in understanding concepts related to palliative care (Pastrana et al., 2008; O'Connor et al., 2010; Bausewein and Higginson, 2012; Papavasiliou et al., 2013; Maciasz et al., 2013; Ewert, et al., 2016). These included discussions of a perceived need to clearly define identified specific terms, e.g. palliative sedation (Papavasiliou et al., 2013); integrated palliative care (Ewert et al., 2016). This thesis has gone further by examining a breadth of conceptions of the approach to the end-of-life, inductively without pre-defining terms of interest. I have argued, based on these findings, that understanding the approach to the end-of-life is conceptualised in dynamic and subjective ways, informed by practice in practitioner-dependent ways.

I have connected this to the difficulties faced in practice by doctors enacting appropriate care for patients approaching the end-of-life. Existing literature has identified challenges for doctors understanding palliative care (Hanratty et al., 2006), recognising dying (Redman et al., 2017), ceasing treatments with life-prolonging intent (Harris and Murray, 2013), and enacting good quality end-of-life care (Shipman et al., 2008). This includes identified challenges for junior doctors (Luthy et al., 2009; Gibbins et al., 2010). Instances of poor end-of-life care have been claimed as linked to the doctor's interpretation (or misinterpretation) of whether or not a patient is dying (Neuberger, 2013; Parlimentary and Health Service Ombudsman, 2014), and over-medicalised death in hospitals as negative experiences (Rhodes-Kropf et al., 2005). Furthermore, the lack of preparation for care of the dying as medical students (Gibbins, et al., 2011; Bowden et al., 2013) and development of skills in care of the dying only after beginning practice have been noted (Price and Schofield, 2015). I

have gone further by comprehensively exploring how new doctors experience elements in practice which, over time, mediate and often challenge understandings of the approach to the end-of-life, and how these elements influence provision of care for these patients. Although previous authors have identified factors which cognitively influence decision-making of UK doctors in care of the dying (Charman and Esterhuizen, 2016; Taylor et al., 2017), I have explored the broader concept – the approach to the end-of-life – rather than only pre-defining one conception (recognising dying or decision-making). My research has taken a socio-material position allowing me to explore how knowledge is constructed and re-constructed through interaction with workplace factors.

I have argued that practice-based factors influence the development of understandings among doctors and may facilitate or challenge their practice. Organisational factors are well established as contributing to instances of poor patient care (Kohn, et al., 2000). I have built on arguments proposed by previous authors that the learning of doctors in practice occurs through practice, not as peripheral participants in the workplace, but as practitioners who are integral to the work of the hospital (Fuller and Unwin, 2004). Organisational factors in the workplace affecting the work of junior doctors have been identified, for example level of autonomy shifting based on time of day, and differing levels of support to junior doctors (Rotella et al., 2014) including in end-of-life care (Price and Schofield, 2015). I have described the organisation of the hospital as being orientated towards providing life-prolonging treatment, which is at odds with the perceived needs for good care of patients approaching the end-of-life. This parallels with findings from Chan (Chan, 2014; Chan et al., 2017) who carried out a focused ethnography in an acute medical ward in Canada and identified a “curative/palliative cultural clash” which constrained the

provision of appropriate care for the dying. However, the Canadian context of this research limited the transferability of the findings to the UK context, and therefore my research makes a valuable contribution by generating comparable findings in a UK context. I have also gone further than previous authors by incorporating a framework to theorise how the workplace factors mediate the actions of practitioners, how these elements interact to provide challenges to practice and learning, and postulate about how these challenges may be targets for future change.

Furthermore, I believe my research is novel within its cultural context. I have reviewed the abstracts of 308 texts identified by a recent comprehensive scoping review of Scottish research related to palliative care from 2006-2015 (Finucane et al., 2017) and did not identify any research which is comparable to my own (other than which has been referenced above). Additionally, my comprehensive literature searches throughout the period of research (which extends to 2019) have not identified any recent comparable study of doctors in a Scottish or UK context in existence. Therefore, in summary, this thesis provides a valuable contribution to existing literature which is novel and useful. It has confirmed and built upon previous authors' works, as has been discussed, and incorporated existing theory to conceptualise how the findings may be usefully applied to practice. Furthermore, it establishes the grounding for further valuable research and development, as will be discussed below.

7.6. Future research and development

As described above, in addressing its aims, this thesis makes a significant contribution to existing literature, and has led to further research questions and identified other areas for development. This section will discuss proposed next stages in research and development.

7.6.1. Other activity systems

Further research should involve exploration of the practice of other members of the multi-disciplinary team. This thesis has explored the learning and understandings of doctors, developing a theory of how new doctors learn and are challenged as they are integrated into the workplace. Building on a CHAT framework, foundation doctors can be understood as part of a wider community, and it is their interactions with other humans and with materials in their environment that mediate their activity. The primary data generated represents the major role of interactions with consultant doctors and nurses on mediating foundation doctors' practice. These other practitioners will also be carrying out activity, and it cannot be assumed that their activity is mediated in the same way or that their objects are aligned. Investigating how these systems of activity compare and conflict would elucidate where contradictions lie in the hospital system in the care of patients approaching the end-of-life. In terms of CHAT, these may be considered as quaternary contradictions, i.e. between interacting activity systems.

Furthermore, the perception of foundation doctors is that they operate within a system which favours the consultant as the expert and the junior doctor is viewed as the novice. However, understanding and discerning treatment decisions for patients approaching the end-of-life may be challenging and uncertain even for more experienced clinicians, and different consultants may advise different treatment plans for the same patient with a life-threatening condition (Greene, 2013). Conversely, consultants may be much more able to navigate uncertainty in clinical practice than junior doctors (Lawton et al., 2019). Investigating the experiences and perceptions of other practitioners – including consultant doctors – are likely to develop insights about this area of healthcare practice not elucidated so far.

This is particularly important as aims for improving educational practice should not only be those which benefit junior doctors. Workplace learning spans all stages of the medical career (Morris and Blaney, 2011), and periods of transition are difficult at all stages of the training and learning within medicine (Westerman et al., 2013), therefore it should not be assumed that senior doctors do not lack educational needs in this area. Furthermore, the need for interprofessional approaches to education in care of dying patients has been identified (Hall et al., 2006; Pahor and Rasmussen, 2009). Developing a richer picture of the activity of all members of the multi-disciplinary team involved in caring for patients approaching the end-of-life will help examine where contradictions lie in practice, and potentially lead to educational implications which will be beneficial to all members of the team.

7.6.2. Deepening understanding of the material world

This thesis has taken a macroscopic view of the workplace learning of doctors, developing broad theoretical claims about practice in the UK general hospital generally. In the future, a more focused study would be useful in order to examine practice in one site of learning. Such a focus on activity within one department may provide great detail about how specific workplace factors influence practice, and how practitioners interact with one another in that workplace. This research may incorporate semi-structured interviews with practitioners, document analysis, and the researcher observations over a prolonged period of engagement. As discussed in section 7.4.1, combining such methods would likely lead to unique insights that cannot be generated through one method alone, and allow data generation that does not rely on the meanings each individual participant makes of their environment and workplace (Robson and McCartan, 2016). This corresponds with the CR philosophical idea that events exist whether they are empirically experienced. Invisible generative mechanisms at work can never fully be understood or perceived, but taking a different approach may contribute to a more complete theory of why things occur the way they do in the workplace (Edwards, et al., 2014b).

Such research may incorporate a methodology such as Institutional Ethnography (IE). IE is a diverse methodology which explores people's work (both paid and unpaid, including taken-for-granted work) as co-ordinated in institutions, and has been used for investigating practice within large organisations (Dent, 2015; Corman and Barron, 2017) but is only recently gaining attention in medical education (Kearney et al., 2019). IE involves the researcher developing a 'problematic': a programme of research which directs investigation to questions, tensions or puzzles

(Kearney et al., 2019) with a commitment to observing the material conditions of the worker's standpoint in the everyday material world (Ng, et al., 2017).

This would be a particularly pertinent methodology for further research into doctors' workplace learning about the approach to the end-of-life. IE accepts work as work if it involves time, effort and intent, incorporating both acknowledged work, and work which is not normally acknowledged by others (Dent, 2015; Corman and Barron, 2017). Furthermore, IE incorporates the concept of disjuncture: disconnection between people's experiences of the world and the representations that come from authoritative, ruling sources. The disjuncture may lead to the researcher developing the problematic (Ng, et al., 2017). This corresponds with this area of study, e.g. the discrepancy between the role of the foundation doctor in the subject's own experience and their perceived place as represented by authoritative sources; the disconnection between good practice in identifying dying patients in guidelines and the perceived reality of practice as indicated by my findings. Taking a more focused study approach, likely incorporating IE in a single site of work, would lead to nuanced findings about the influences on work for the individuals involved.

7.6.3. Patient perspective

As described above (Section 7.4.5) this research can be criticised for its lack of consideration of patients' perspectives. The workplace learning perspective I have taken, including incorporating CHAT, has centred the worker. However, high quality care should be patient-centred (Mulley, et al., 2012), and it is not good practice to take a paternalistic attitude towards patients (Royal College of Physicians, 2013).

Doctor-centric understandings may increase power over the patient, which is particularly important for end-of-life care, when patients may lack agency (Campbell et al., 2014; Brighton and Bristowe, 2016). Furthermore, I have identified multiple conceptions among doctors; therefore understandings cannot be expected to be uniformly shared between doctors and patients. I have asserted that the views of junior doctors should be taken seriously in determining what is good care, but the patient view is also of vital importance.

Further research should therefore consider how the patient experiences and understands the approach to the end-of-life. Such research would require careful ethical and methodological planning in order to recruit a relevant sample of patients who had gone through the change from the object of life-prolonging care to the object of care of the dying. This may have similarities with research by MacArtney et al (2015) who investigated experience of patients who had made the 'transition to palliative care' at a specialist palliative care unit in Australia. However, the data and their results centred on experiences of inpatient specialist palliative care, and personal reflections on illness and dying. While this provides valuable knowledge, this does not correspond with the necessary further research of patient perspective about the approach to end-of-life for various reasons: the authors focused on specialist palliative care rather than broader experiences of the approach to the end-of-life; the study focused on personal views of the patient's illness and mortality, rather than interactions with the healthcare system and practitioners; the study was not conducted in the UK which limits its transferability. Future research should therefore carry out more information addressing these research gaps. The findings of such study may inform future iterations of patient care.

7.6.4. The change laboratory

As discussed in Chapter 6, from a CHAT viewpoint, the overcoming of contradictions to develop new forms of an activity is described as expansive transformation (Engeström, 1987). Generating change within an organisation is challenging, and may require multiple small cycles of innovation, during which changes are evaluated and refined. Engeström describes these as expansive cycles. Expansive transformation can involve formative interventions, during which contradictions are analysed by members of the community, and innovations are devised (Engeström, 1987). Effective transformation requires practitioners to have agency to take initiative and recommend and plan for changes away from established ways of doing things (Larson, et al., 2019).

Formative interventions, for example, take place at the Centre for Research, Activity, Development and Learning research centre in Helsinki and include the Change Laboratory. The Change Laboratory is a structured, contrived activity which consists of multiple sessions occurring over several months, during which practitioners are presented with a work activity by a researcher. A 'mirror' is provided which represents daily work (e.g. a videotaped episode of work). The researcher facilitates the workers in mapping workplace activity to the CHAT framework, and then helps participants be mindful of contradictions in the system. Participants then devise the future model which resolves the contradictions, including a plan for examining and implementing the new model (Kerosuo, et al., 2010).

Potentially, the Change Laboratory approach could be useful for expansive transformation in hospital care for patients approaching the end-of-life. This would

involve presentation of a ‘mirror’ which has been informed by the preceding exploratory research. In devising innovation, all members of the multi-disciplinary team – including foundation doctors – would be empowered to contribute to changing their own system of practice.

7.7. Summary of discussion

This discussion has drawn upon the work presented in this thesis to construct an explanation of how the approach to the end-of-life is understood and learned about. I have argued that these understandings are subjective, not biologically essentialist, and developed dynamically through practice. They are therefore not developed prior to starting work as a doctor. Doctors operate within a hospital system designed to preferentially provide life-prolonging healthcare. Foundation doctors have responsibility for care of sick and deteriorating patients, which inevitably will include those at the approach to the end-of-life, but the degree of responsibility afforded varies based on systemic factors, not educational or patient needs. Various organisational factors affect the doctor in understanding the patient’s condition and being able to provide care. When tensions are experienced, foundation doctors may feel they are not facilitated to be able to take appropriate actions, which they perceive as leading to poor patient care for patients approaching the end-of-life. Overcoming challenges in practice should include centring those who are at the forefront of providing end-of-life care – including junior doctors – and facilitating them in being agents of change in the systems in which they operate. Although there are likely to be challenges, it will be fruitful to empower them to work towards finding new ways of systems working to improve practice, learning and patient care.

This work has limitations including its lack of incorporating observations of practice and patient perspective, and its workplace focus potentially neglecting medical school perspectives and wider cultural influences. Nevertheless, this work has drawn on and built upon numerous existing theories and research traditions in order to connect education, practice studies, and end-of-life care into a meaningful contribution to literature with significant implications for practice. Furthermore, it establishes the grounding for further valuable research, including investigating the patient perspective and the activity of other healthcare professionals. Building on my findings, innovations for improved practice should be generated through the voices of the involved workers, potentially using a Change Laboratory approach. I hope that this thesis serves as a valuable steppingstone to improved learning and practice, and better care for patients at the approach to the end-of-life.

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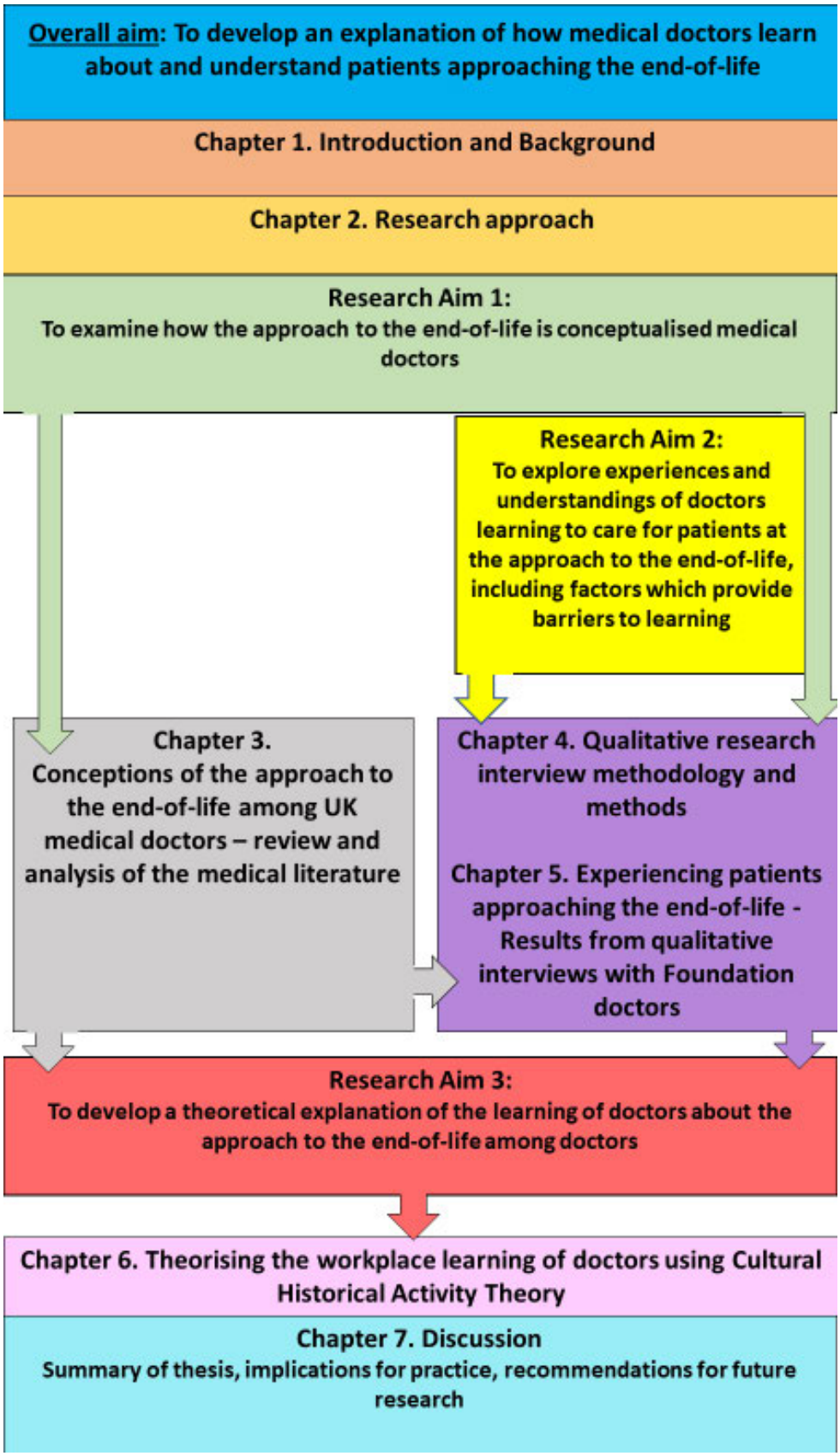
Appendix 1: Thesis structure



Appendix 2. Interview Participant information

Learning About Medicine's Limitations

University of Edinburgh Centre for Medical Education

Interview Participant Information

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Contact us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

We are investigating the experiences of foundation doctors in cases where medicine's capacity to cure was limited. We are looking for foundation doctors who are willing to take part in one-on-one interviews and speak about experiences where patients under their care could not be cured of their illness. In particular, we are seeking to discover what was learned by the doctors in these cases, if there were any difficulties, and how (or if) doctors are prepared for these situations. We hope that the findings can contribute to improved teaching and learning in medical schools to better prepare new doctors for these kinds of situations.

This research is needed because the medical management of patients who will not be cured of their disease is an important part of a doctor's role. This is becoming ever more pertinent with greater numbers of people living with chronic conditions, an increasing focus on anticipatory care and governmental drives to reduce inappropriate over treatment of patients. Learning about the recognition and management of these issues in patient care is complex and often uncertain. Undergraduate preparation in this area is inconsistent and may be inadequate.

Why have I been asked to take part?

Previous studies indicate that medical students are not aware of many patients who cannot be cured of their illness, and it is only after starting work as a doctor do they realise the extent to which managing these patients is a major part of their work. Foundation doctors have made the transition from medical student to practicing medical professional more recently than more senior doctors. We wish to get their perspective of foundation doctors in order to investigate what was learned over this period of transition.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. Deciding not to take part or withdrawing from the study will not affect your career progression or training.

What will happen if I take part?

You will be asked to participate in a one-on-one interview with the researcher. This will last 90 minutes or less. The interviewer is the primary investigator in this study. He is a physician trainee who is currently employed as an Education Fellow within the University of Edinburgh Centre for Medical Education.

Interviews can be planned around your other commitments. The interview will be recorded. If you agree to participate you will be asked to sign a consent form. After the interview, the recording will be transcribed and analysed.

What Will I Be Asked?

The interview will focus on times when you realised a patient was not improving despite medical treatment, and how you see your learning and preparation for these scenarios. You will be also asked about your site of undergraduate degree, current stage of post-graduate training and, and the rotations you have had so far in post-graduate training. The interviews will be semi-structured: although they will follow the above structure, the questions asked will be open ended and the direction of the interview may change depending on the answers.

What are the possible benefits of taking part?

This is an opportunity to speak confidentiality with a doctor who does not work with you directly and is not involved in your supervision or management. It will provide a non-judgemental environment to discuss issues that affect you.

It is also an opportunity to participate in valuable research. By contributing to the study, we hope that you will be leading to positive change within undergraduate medical training. It may also give you an insight into different research techniques and approaches. You will have the opportunity to see the results when the study is completed

What are the possible disadvantages and risks of taking part?

You are being asked to give up your free time to participate in this study. You will not be paid for participating, but every effort will be made to hold the interviews at times which are convenient for you and which minimise potential disruption to your work pattern.

Information that you disclose in the interviews will not routinely be revealed to any other parties in a way which can be traced back to you. However, if you reveal specific information which leads to serious concerns for patient safety the researcher will be obliged to take action. This action will require the information divulged to be passed onto responsible staff within the NHS and may require your identity to be revealed at this time.

What if there is a problem?

If you have a concern about any aspect of this study please contact Dr Shaun Qureshi (shaun.qureshi@ed.ac.uk). Dr. Qureshi will do his best to answer your questions.

Will my taking part in the study be kept confidential?

Confidentiality of all participants will be maintained. The researchers will not reveal who has and who has not participated in the interviews. The audio recordings will be stored electronically on the secure University of Edinburgh server and data will be transcribed. The data will be anonymised and names replaced with pseudonyms. Anonymised direct quotations may be published to illustrate the findings.

However, patient safety is vital in all research related to medicine. If information is divulged which leads to serious concerns for patient safety the researcher will be obliged to take action, which will require the information divulged to be passed onto responsible staff within the NHS and may require your identity to be revealed at this time.

To ensure that the study is being run correctly, we will ask your consent for responsible representatives from the Sponsor and NHS Institution to access your consent forms and the data collected during the study, where it is relevant to you taking part in this research. The Sponsor is responsible for overall management of the study and providing insurance and indemnity.

What will happen to the results of the study?

The study will be written up for a research thesis. It is anticipated that it will also be published in relevant journals and presented at academic conferences. You will not be identifiable in any published results. You will have the opportunity to see the summary of the results of the study and any published work. If you wish this, the primary researcher will retain your contact e-mail address and send you electronic copies of the results.

Who is organising the research?

This study has been organised by the University of Edinburgh Centre for Medical Education. It is sponsored by the University of Edinburgh.

Who has reviewed the study?

The study proposal has been reviewed by Dr. Dave Hope, Senior Fellow in Medical Education, University of Edinburgh. NHS management approval has also been obtained.

Further Information

If you would like to discuss this study, or you are interested in participating, then please contact the primary investigator:

Dr. Shaun Qureshi Centre For Medical Education, University of Edinburgh, Chancellor's Building, EH164SB. 0131 242 6412

If you would like to discuss this study with someone independent of the study please contact:

Dr Fay Crawford, Senior Research Advisor, Research and Development Office, Research and Education Centre, Queen Margaret Hospital, Whitefield Road, Dunfermiline, KY12 OSU. 01383 623623 ext 20943

If you wish to make a complaint about the study please contact NHS Fife:

Patient Relations Department, Fife NHS Board, Room 104, Hayfield House, Hayfield Road, Kirkcaldy, KY2 5AH, 01592 643355 Ext 28153 (patientrelations.fife@nhs.net).

Thank you for taking the time to read this information sheet.

Appendix 3. Interview Participant Consent Form

Learning About Medicine's Limitations

University of Edinburgh Centre for Medical Education

Interview Participant Consent Form

Date: _____

Researcher: **Dr Shaun Qureshi**

Researcher email: **shaun.qureshi@ed.ac.uk**

Participant name: _____

Contact email: _____

Please read carefully, initial each point and sign below.

I confirm that I have read and understand the information sheet for the above study and have had the opportunity to consider the information and ask questions	
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.	
I am aware that this interview will not form part of any assessment or judgement of me, will not effect my training progression and that no data gathered during this process will be passed on to my clinical or educational supervisors; **however I understand that if I reveal specific information which leads to serious concerns for patient safety the researcher will be obliged to take action, which will require the information divulged to be passed onto responsible staff within the NHS and may require my identity to be revealed at this time.**	
I do not in any way feel pressured into participating in this research, and will try to respond openly and honestly to the questions.	

I understand that the interview will be audio-recorded and transcribed. The recording and transcript will be kept strictly confidential, anonymised and will only be accessible to the research team. They will be destroyed after 3 years or sooner if no longer required for research purposes.	
I understand that audio recordings will be transferred to a transcription service via a secure web server and will be treated confidentially by that service. My personal details will not be attached to this recording.	
I understand that the findings of this study will form part of a research thesis to be submitted to the University of Edinburgh and may be published or presented at conferences. All data will be anonymised.	
I agree to the use of anonymised quotes from the transcript of the interview in publication of the research findings.	
I understand that data collected during the study may be looked at by individuals from the Sponsor, from the NHS organisation or other authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
I agree to take part in the above study.	
(Optional) I wish to receive further updates about the progress of this study and any published findings and consent to my contact details being retained for this purpose	

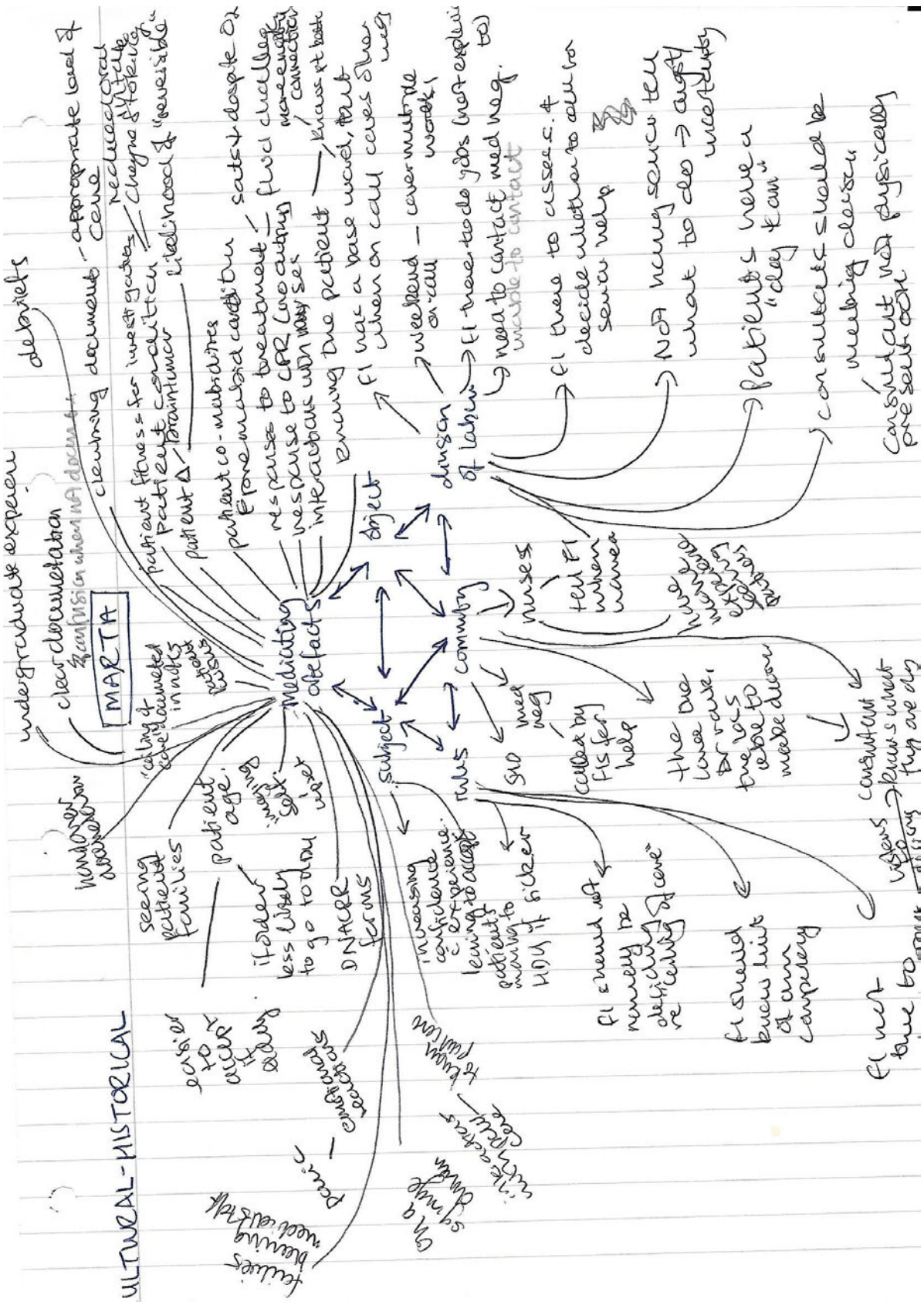
Please read carefully and sign below.

_____	_____	_____
Name of Participant	Date	Signature

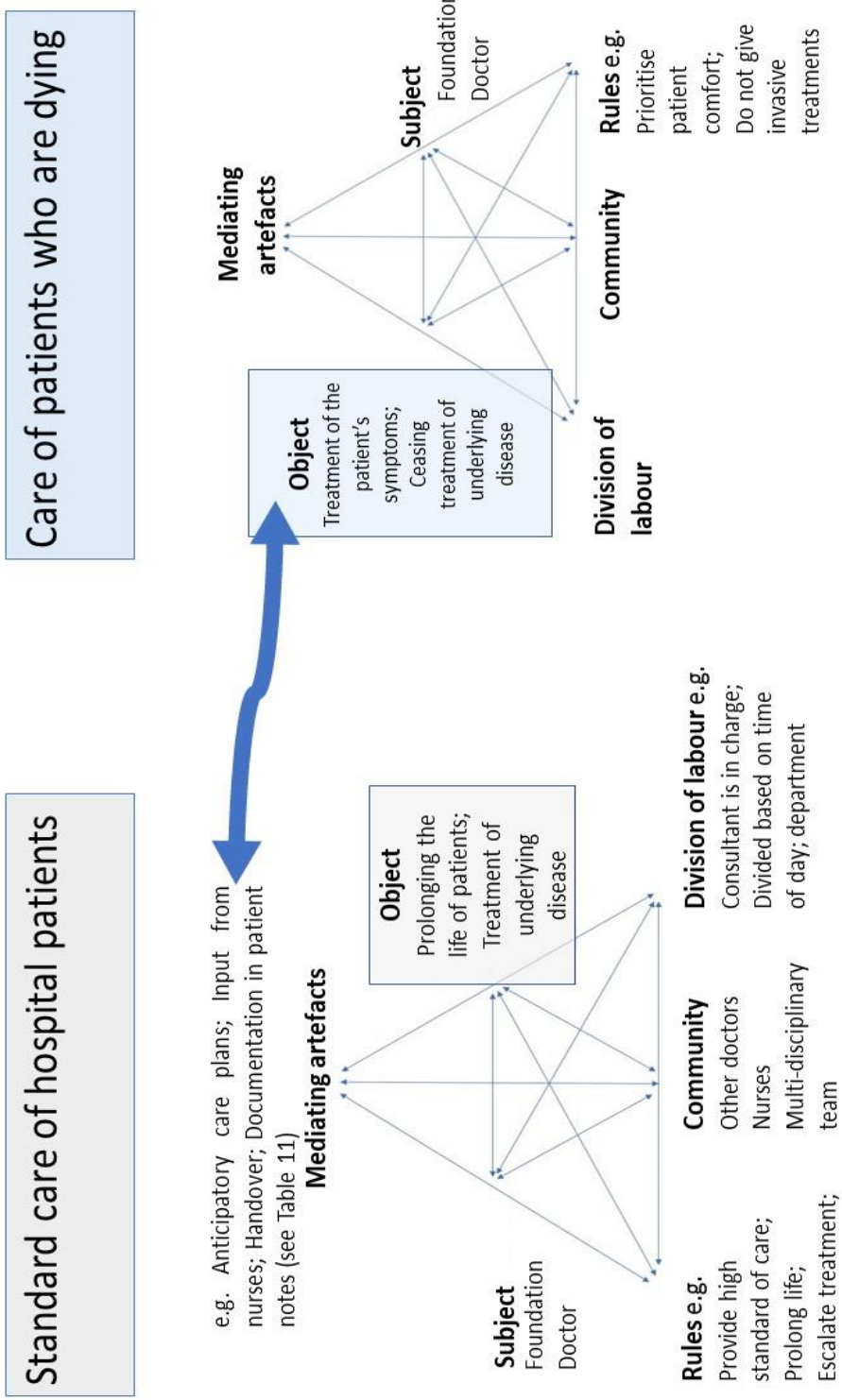
_____	_____	_____
Name of Person taking consent	Date	Signature

One copy to be retained by researcher
One copy to be given to research participant

Appendix 4. Example of Activity Systems Analysis



Appendix 5. Activity system of doctors learning about patients approaching the end-of-life in the workplace.



Appendix 6. Documents identified using Scoping Study Methodology included in Qualitative Content Analysis

Author	Year	Title	Publication Title	Type
Aapro, M.; Arends, J.; Bozzetti, F.; Fearon, K.; Grunberg, S. M.; Herrstedt, J.; Hopkinson, J.; Jacquelin-Ravel, N.; Jatoi, A.; Kaasa, S.; Strasser, F.	2014	Early recognition of malnutrition and cachexia in the cancer patient: a position paper of a European School of Oncology Task Force	Annals of Oncology	Position Paper
Ahearn, David Jonathan; Nidh, Niamh; Kallat, Arun; Adenwala, Yousouf; Varman, Surendra	2013	Offering older hospitalised patients the choice to die in their preferred place	Postgraduate Medical Journal	Study - Retrospective case note review
Ahmed, Nisar; Hughes, Philippa; Winslow, Michelle; Bath, Peter A.; Collins, Karen; Noble, Bill	2015	A Pilot Randomized Controlled Trial of a Holistic Needs Assessment Questionnaire in a Supportive and Palliative Care Service	Journal of Pain and Symptom Management	Study - RCT of holistic needs assessment questionnaire
Alifrangis, C.; Koizia, L.; Rozario, A.; Rodney, S.; Harrington, M.; Somerville, C.; Peplow, T.; Waxman, J.	2011	The experiences of cancer patients	Qjm-an International Journal of Medicine	Study - questionnaire
Al-Qurainy, R.; Collis, E.; Feuer, D.	2009	Dying in an acute hospital setting: the challenges and solutions.	International journal of clinical practice	Study - review
Ambrosino, Nicolino; Simonds, Anita	2007	The clinical management in extremely severe COPD	Respiratory Medicine	Clinical guidance
Andersen, Peter M.; Abrahams, Sharon; Borasio, Gian D.; de Carvalho, Mamede; Chio, Adriano; Van Damme, Philip; Hardiman, Orla; Kollewe, Katja; Morrison, Karen E.; Petri, Susanne; Pradat, Pierre-Francois; Silani, Vincenzo; Tomik, Barbara; Wasner, Maria; Weber, Markus	2012	EFNS guidelines on the Clinical Management of Amyotrophic Lateral Sclerosis (MALS) - revised report of an EFNS task force	European Journal of Neurology	Study - review of clinical guidelines

Andersen, Peter Munch; Borasio, Gian Domenico; Dengler, Reinhard; Hardiman, Orla; Kollewe, Katja; Leigh, Peter Nigel; Pradat, Pierre-Francois; Silani, Vincenzo; Tomik, Barbara	2007	Good practice in the management of amyotrophic lateral sclerosis: Clinical guidelines. An evidence-based review with good practice points. EALSC Working Group	Amyotrophic Lateral Sclerosis	Study - review of clinical guidelines
Arnold, Elizabeth; Finucane, Anne M.; Oxenham, David	2015	Preferred place of death for patients referred to a specialist palliative care service	Bmj Supportive & Palliative Care	Study - Retrospective case note review
Arolker M; Barnes J; Gadoud A; Jones L; Barnes L; Johnson MJ	2010	'They've got to learn' -- a qualitative study exploring the views of patients and staff regarding medical student teaching in a hospice.	Palliative Medicine	Study - qualitative study of views of patients in hospice
Arris, Steven M.; Fitzsimmons, Deborah A.; Mawson, Susan	2015	Moving towards an enhanced community palliative support service (EnComPaSS): protocol for a mixed method study	Bmc Palliative Care	Study - (protocol) mixed methods for a development of model for investigating community palliative care service
Audrey S; Abel J; Blazeby JM; Falk S; Campbell R	2008	What oncologists tell patients about survival benefits of palliative chemotherapy and implications for informed consent: qualitative study.	BMJ: British Medical Journal (International Edition)	Study - qualitative study of consultations between oncologists and palliative care services
Bajwah, Sabrina; Higginson, Irene J.; Ross, Joy R.; Wells, Athol U.; Birring, Surinder S.; Patel, Amit; Riley, Julia	2012	Specialist Palliative Care is More Than Drugs: A Retrospective Study of ILD Patients	Lung	Study - Retrospective case note review
Bajwah, Sabrina; Higginson, Irene J.; Ross, Joy R.; Wells, Athol U.; Birring, Surinder S.; Riley, Julia; Koffman, Jonathan	2013	The palliative care needs for fibrotic interstitial lung disease: A qualitative study of patients, informal caregivers and health professionals	Palliative Medicine	Study - qualitative study of specialist palliative care needs of people living with end stage fibrotic interstitial lung disease

Bajwah, Sabrina; Ross, Joy R.; Wells, Athol U.; Mohammed, Kabir; Oyebode, Christina; Birring, Surinder S.; Patel, Amit S.; Koffman, Jonathan; Higginson, Irene J.; Riley, Julia	2015	Palliative care for patients with advanced fibrotic lung disease: a randomised controlled phase II and feasibility trial of a community case conference intervention	Thorax	Study - RCT to investigate impact of case conference intervention delivered in the home
Bakhai K; O'Sullivan C; Riley J	2013	End-of-life care: identification, communication, training, and commissioning.	British Journal of General Practice	Editorial
Barclay S; Maher J	2010	Having the difficult conversations about the end of life.	BMJ: British Medical Journal (Overseas & Retired Doctors Edition)	Spotlight article - Having difficult conversations
Barclay S; Momen N; Case-Upton S; Kuhn I; Smith E	2011	End-of-life care conversations with heart failure patients: a systematic literature review and narrative synthesis.	British Journal of General Practice	Study - Systematic Review and Narrative Review
Barclay, Stephen; Whyte, Rebecca; Thiemann, Pia; Benson, John; Wood, Diana F.; Parker, Richard A.; Quince, Thelma	2015	An important but stressful part of their future work: medical students' attitudes to palliative care throughout their course.	Journal of pain and symptom management	Study - questionnaire of medical students towards palliative care
Barnes, Julia; Campbell, Colin	2010	Palliative care in multiple sclerosis and motor neurone disease	British Journal of Hospital Medicine	Symposium on Extending Palliative Care
Barnes, Sarah; Gardiner, Clare; Gott, Merryn; Payne, Sheila; Chady, Becky; Small, Neil; Seamark, David; Halpin, David	2012	Enhancing Patient-Professional Communication About End-of-Life Issues in Life-Limiting Conditions: A Critical Review of the Literature	Journal of Pain and Symptom Management	Study - critical literature review
Bausewein, Claudia; Higginson, Irene J.	2012	Challenges in defining 'palliative care' for the purposes of clinical trials	Current Opinion in Supportive and Palliative Care	Study - review
Beckett, Daniel J.; Inglis, Monica; Oswald, Sharon; Thomson, Elaine; Harley, Wilma; Wilson, Jennifer; Lloyd, Robert C.; Rooney, Kevin D.	2013	Reducing cardiac arrests in the acute admissions unit: a quality improvement journey	Bmj Quality & Safety	Report of clinical quality improvement

Beecham, Emma; Candy, Bridget; Howard, Richard; McCulloch, Renée; Laddie, Jo; Rees, Henrietta; Vickerstaff, Victoria; Bluebond-Langner, Myra; Jones, Louise	2015	Pharmacological interventions for pain in children and adolescents with life-limiting conditions	Cochrane Database of Systematic Reviews	Study - systematic review
Bennett, Frances; Brodrick, Robert; Stirling, L. Caroline	2015	Dying for a change: junior doctors and care of the dying patient.	British journal of hospital medicine (London, England : 2005)	Clinical guidance
Beringer, A. J.; Heckford, E. J.	2014	Was there a plan? End-of-life care for children with life-limiting conditions: a review of multi-service healthcare records	Child Care Health and Development	Study - Retrospective case note review
Bingley, A. F.; McDermott, E.; Thomas, C.; Payne, S.; Seymour, J. E.; Clark, D.	2006	Making sense of dying: a review of narratives written since 1950 by people facing death from cancer and other diseases	Palliative Medicine	Study - qualitative content analysis of narratives
Birch, Deborah; Draper, Jan	2008	A critical literature review exploring the challenges of delivering effective palliative care to older people with dementia	Journal of Clinical Nursing	Study - critical literature review
Blackwood, D.; Santhirapala, R.; Mythen, M.; Walker, D.	2015	End of life decision planning in the perioperative setting: the elephant in the room?	BJA: The British Journal of Anaesthesia	Editorial
Boland, Jason; Martin, Jonathan; Wells, Athol U.; Ross, Joy R.	2013	Palliative care for people with non-malignant lung disease: Summary of current evidence and future direction	Palliative Medicine	Clinical guidance
Bond, Catherine Jane; Lowton, Karen	2011	Geriatricians' views of advance decisions and their use in clinical care in England: qualitative study.	Age and ageing	Study - qualitative study of geriatricians views on advance decisions
Borgstrom, Erica; Barclay, Stephen; Cohn, Simon	2013	Constructing denial as a disease object: accounts by medical students meeting dying patients.	Sociology of health & illness	Study - qualitative study of medical students accounts
Bourke, S. J.; Doe, S. J.; Gascoigne, A. D.; Heslop, K.; Fields, M.; Reynolds, D.; Mannix, K.	2009	An integrated model of provision of palliative care to patients with cystic fibrosis	Palliative Medicine	Study - Retrospective case note review

Bowden, J.; Dempsey, K.; Boyd, K.; Fallon, M.; Murray, S. A.	2013	Are newly qualified doctors prepared to provide supportive and end-of-life care? A survey of Foundation Year 1 doctors and consultants.	The journal of the Royal College of Physicians of Edinburgh	Study - survey and qualitative interviews with foundation doctors
Boyd, Kirsty J.; Worth, Allison; Kendall, Marilyn; Pratt, Rebekah; Hockley, Jo; Denvir, Martin; Murray, Scott A.	2009	Making sure services deliver for people with advanced heart failure: a longitudinal qualitative study of patients, family carers, and health professionals	Palliative Medicine	Study - longitudinal qualitative study
Bradley, Sarah Elizabeth; Frizelle, Dorothy; Johnson, Miriam	2011	Why Do Health Professionals Refer Individual Patients to Specialist Day Hospice Care?	Journal of Palliative Medicine	Study - qualitative study of reasons for referral to day hospice
Brazil, Kevin; Carter, Gillian; Galway, Karen; Watson, Max; van der Steen, Jenny T.	2015	General practitioners perceptions on advance care planning for patients living with dementia.	BMC palliative care	Study - cross sectional study exploring GPs opinions of dementia ACPs
Brierly, Robert D.; O'Brien, Tim S.	2008	The importance of palliative care in urology	Urologia Internationalis	Study - prospective and retrospective observations to determine if SPC referral would benefit
Brighton, Lisa Jane; Bristowe, Katherine	2016	Communication in palliative care: talking about the end of life, before the end of life	Postgraduate Medical Journal	Review
Brims, Fraser J. H.; Kilminster, Shaun; Thomas, Lynn M.	2009	Resuscitation decisions among hospital physicians and intensivists.	Clinical medicine (London, England)	Study - questionnaire to medical staff about differences in attitudes and confidence in decision making
British Medical Association	2014	BMA - End-of-life care and physician-assisted dying		Policy document
Brooks, David	2014	Care of the dying: priorities for the future.	British Journal of Hospital Medicine (17508460)	Editorial

Burki TK	2013	End-of-life discussions and care received.	Lancet Oncology	News
Burt J; Raine R	2006	The effect of age on referral to and use of specialist palliative care services in adult cancer patients: a systematic review.	Age & Ageing	Study - systematic review examining use of or referral to SPC services in adult cancer patients
Burt, Jenni; Shipman, Cathy; Richardson, Alison; Ream, Emma; Addington-Hall, Julia	2010	The experiences of older adults in the community dying from cancer and non-cancer causes: a national survey of bereaved relatives	Age and Ageing	Study - retrospective cross-sectional survey of bereaved relatives
Burt, Jenni; Shipman, Cathy; White, Patrick; Addington-Hall, Julia	2006	Roles, service knowledge and priorities in the provision of palliative care: a postal survey of London GPs	Palliative Medicine	Study - cross sectional survey exploring GPs involvement in and attitudes to provision of palliative care in primary care
Butler, Claire; Holdsworth, Laura M.; Coulton, Simon; Gage, Heather	2012	Evaluation of a hospice rapid response community service: a controlled evaluation	Bmc Palliative Care	Study - protocol for quasi-experimental controlled trial
Campbell, Malcolm; Grande, Gunn; Wilson, Charlotte; Caress, Ann-Louise; Roberts, Dai	2010	Exploring differences in referrals to a hospice at home service in two socio-economically distinct areas of Manchester, UK	Palliative Medicine	Study - Retrospective case note review
Carey Irene, Smtih Robert, Shouls Susanna	2015	Transforming End of Life Care in Acute Hospitals AM Workshop 2: AMBER Care Bundle		Clinical guidance
Caswell, Glenys; Pollock, Kristian; Harwood, Rowan; Porock, Davina	2015	Communication between family carers and health professionals about end-of-life care for older people in the acute hospital setting: a qualitative study	Bmc Palliative Care	Study - qualitative study aiming to understand factors and processes affecting quality of care provided to frail older people who are dying in hospital and their family carers

Cawley D; Waterman D; Roberts D; Caress A	2011	A qualitative study exploring perceptions and experiences of patients and clinicians of palliative medicine outpatient clinics in different settings.	Palliative Medicine	Study - qualitative exploration of patient experience
Chahl P; Bond A	2009	'I'm sorry but you've got cancer': The role of psycho-oncology.	British Journal of Hospital Medicine (17508460)	Review
Chan RJ, Webster J, Bowers A	2016	End-Of-Life Care Pathways for Improving Outcomes in Caring for the Dying (Review)		Study - Systematic Review
Charalambous, Haris; Pallis, Athanasios; Hasan, Baktiar; O'Brien, Mary	2014	Attitudes and referral patterns of lung cancer specialists in Europe to Specialized Palliative Care (SPC) and the practice of Early Palliative Care (EPC)	BMC Palliative Care	Study - cross sectional survey examining availability of palliative care services and referral patterns of European Lung cancer specialists to palliative care
Charman, Lesley Ann; Esterhuizen, Philip	2016	A nurse's phenomenological enquiry into doctors' end-of-life decision making.	Journal of Research in Nursing	Study - qualitative study exploring lived experience of decision making for oncology patients near the end of life
Chattoo, Sangeeta; Atkin, Karl M.	2009	Extending specialist palliative care to people with heart failure: Semantic, historical and practical limitations to policy guidelines	Social Science & Medicine	Review
Chinthapalli, Krishna	2013	The Liverpool care pathway: what do specialists think?	BMJ (Clinical research ed.)	News
Clarke, G.; Johnston, S.; Corrie, P.; Kuhn, I.; Barclay, S.	2015	Withdrawal of anticancer therapy in advanced disease: a systematic literature review	Bmc Cancer	Study - systematic literature review
Coad, Jane; Kaur, Jasveer; Ashley, Nicky; Owens, Christopher; Hunt, Anne; Chambers, Lizzie; Brown, Erica	2015	Exploring the Perceived Met and Unmet Need of Life-Limited Children, Young People and Families	Journal of Pediatric Nursing-Nursing Care of Children & Families	Study - qualitative exploration of perceived met and unmet needs of services and care

Cocks, H.; Ah-See, K.; Capel, M.; Taylor, P.	2016	Palliative and supportive care in head and neck cancer: United Kingdom National Multidisciplinary Guidelines	Journal of Laryngology and Otology	Clinical guidance
Cohen, J.; Bilsen, J.; Addington-Hall, J.; Lofmark, R.; Miccinesi, G.; Kaasa, S.; Onwuteaka-Philipsen, B.; Deliens, L.	2008	Population-based study of dying in hospital in six European countries	Palliative Medicine	Study - retrospective analysis to examine proportion of deaths taking place in hospitals
Collis, Emily; Sleeman, Katherine E.	2013	Do patients need to know they are terminally ill? Yes	Bmj-British Medical Journal	Opinion
Coombs, Maureen A.; Addington-Hall, Julia; Long-Sutehall, Tracy	2012	Challenges in transition from intervention to end of life care in intensive care: A qualitative study.	International Journal of Nursing Studies	Study - Qualitative study to identify challenges for health care professionals when moving from a recovery trajectory to an end of life trajectory in intensive care
Coupland, Victoria H.; Madden, Peter; Jack, Ruth H.; Moller, Henrik; Davies, Elizabeth A.	2011	Does place of death from cancer vary between ethnic groups in South East England?	Palliative Medicine	Study - retrospective analysis to investigate whether place of death from cancer differs between ethnic groups
Creagh-Brown, B. C.; Shee, C.	2009	Palliative and end-of-life care for patients with severe COPD	European Respiratory Journal	Letter to Editor
Crosby, Vincent; Wilcock, Andrew	2011	End-of-life care in rheumatology Room for improvement	Rheumatology	Letter to Editor
Dale, J.; Petrova, M.; Munday, D.; Koistinen-Harris, J.; Lall, R.; Thomas, K.	2009	A national facilitation project to improve primary palliative care: impact of the Gold Standards Framework on process and self-ratings of quality	Quality & Safety in Health Care	Study - questionnaire exploring GPs that participated in the GSF
Danbury, C. M.; Waldmann, C. S.	2006	Ethics and law in the intensive care unit.	Best practice & research.	Book Chapter

			Clinical anaesthesiology	
Davies, Nathan; Maio, Laura; Vedavanam, Krish; Manthorpe, Jill; Vernooij-Dassen, Myrra; Iliffe, Steve	2014	Barriers to the provision of high-quality palliative care for people with dementia in England: a qualitative study of professionals' experiences.	Health & social care in the community	Study - qualitative interviews exploring perceived barriers to the delivery of high-quality palliative care for people with dementia
Davis, Courtney	2015	Drugs, cancer and end-of-life care: A case study of pharmaceuticalization?	Social Science & Medicine	Opinion
De Witt Jansen, Bannin; Weckmann, Michelle; Nguyen, Christopher M.; Parsons, Carole; Hughes, Carmel M.	2013	A cross-national cross-sectional survey of the attitudes and perceived competence of final-year medicine, nursing and pharmacy students in relation to end-of-life care in dementia.	Palliative medicine	Study - cross-sectional survey of attitudes and perceived competence of final year medicine
Dehnel, Tim	2014	Should intensive care medics be palliative specialists?	The Lancet. Respiratory medicine	Opinion
Denvir, Martin A.; Highet, Gill; Robertson, Shirley; Cudmore, Sarah; Reid, Janet; Ness, Andrea; Hogg, Karen; Weir, Christopher; Murray, Scott; Boyd, Kirsty	2014	Future Care Planning for patients approaching end-of-life with advanced heart disease: an interview study with patients, carers and healthcare professionals exploring the content, rationale and design of a randomised clinical trial	Bmj Open	Study - qualitative study to explore optimal content and design of a clinical trial of end-of-life intervention for advanced heart disease with patients, carers and health professionals
Department of Health	2010	End of Life Care Strategy: Second Annual Report - Publications - GOV.UK		Government white paper
Dickinson, George E.; Paul, Elizabeth S.	2015	End-of-Life Issues in UK Medical Schools	American Journal of Hospice & Palliative Medicine	Study - questionnaire study of current status of end-of-life issues in UK medical schools

Dickman, Karen; Carey, Marjorie; Rao, Archana; Worthington, Amanda; Hilton, Linda; Kavanagh, Rory; Cullen, Ann; Gossage, Elaine	2014	Knowsley Trigger Tool - a Tool to Aid Identification of Heart Failure Patients Nearing End of Life and Promote Communication Between Heart Failure Specialist Nurses and Primary Care	Heart	Study - (abstract) Evaluation of a clinical trigger tool for heart failure patients
Etkind SN	2012	Terminal sedation: an emotional decision in end-of-life care.	Journal of Medical Ethics	Case Study
Etkind, S. N.; Koffman, J.	2016	Approaches to managing uncertainty in people with life-limiting conditions: role of communication and palliative care	Postgraduate Medical Journal	Review
Evans, Natalie; Menaca, Arantza; Andrew, Erin V. W.; Koffman, Jonathan; Harding, Richard; Higginson, Irene J.; Pool, Robert; Gysels, Marjolein	2011	Appraisal of literature reviews on end-of-life care for minority ethnic groups in the UK and a critical comparison with policy recommendations from the UK end-of-life care strategy	Bmc Health Services Research	Study - systematic review
Evans, Natalie; Menaca, Arantza; Andrew, Erin V. W.; Koffman, Jonathan; Harding, Richard; Higginson, Irene J.; Pool, Robert; Gysels, Marjolein	2012	Systematic Review of the Primary Research on Minority Ethnic Groups and End-of-Life Care From the United Kingdom	Journal of Pain and Symptom Management	Study - systematic review
Evans, Natalie; Menaca, Arantza; Koffman, Jonathan; Harding, Richard; Higginson, Irene J.; Pool, Robert; Gysels, Marjolein	2012	Cultural Competence in End-of-Life Care: Terms, Definitions, and Conceptual Models from the British Literature	Journal of Palliative Medicine	Study - critical review aiming to appraise cultural competency approaches described in British literature
Evans, Natalie; Pasman, H. Roeline W.; Payne, Sheila A.; Seymour, Jane; Pleschberger, Sabine; Deschepper, Reginald; Onwuteaka-Philipsen, Bregje D.	2012	Older patients' attitudes towards and experiences of patient-physician end-of-life communication: a secondary analysis of interviews from British, Dutch and Belgian patients	Bmc Palliative Care	Study - secondary analysis of interviews with patients
Evans, Rebecca; Finucane, Anne; Vanhegan, Lynsey;	2014	Do place-of-death preferences for patients receiving specialist	International Journal of Palliative Nursing	Study - Retrospective case note review

Arnold, Elizabeth; Oxenham, David		palliative care change over time?		
Ewert, Benjamin; Hodiamont, Farina; van Wijngaarden, Jeroen; Payne, Sheila; Groot, Marieke; Hasselaar, Jeroen; Menten, Johann; Radbruch, Lukas	2016	Building a taxonomy of integrated palliative care initiatives: results from a focus group	Bmj Supportive & Palliative Care	Study - qualitative study
Ewing, G.; Rogers, M.; Barclay, S.; McCabe, J.; Martin, A.; Campbell, M.; Todd, C.	2006	Palliative care in primary care: a study to determine whether patients and professionals agree on symptoms	British Journal of General Practice	Study - prospective self-completed patients questionnaires
Ewing, Gail; Farquhar, Morag; Booth, Sara	2009	Delivering Palliative Care in an Acute Hospital Setting: Views of Referrers and Specialist Providers	Journal of Pain and Symptom Management	Study - qualitative study exploring views of SPC referrers and providers
Faull, Christina; Rowe Haynes, Cassy; Oliver, David	2014	Issues for palliative medicine doctors surrounding the withdrawal of non-invasive ventilation at the request of a patient with motor neurone disease: a scoping study.	BMJ supportive & palliative care	Study - questionnaire aiming to identify issues and challenges that palliative doctors encounter in relation to withdrawal of NIV in MND patients
Fields, Anna; Finucane, Anne; Oxenham, David	2013	Discussing preferred place of death with patients: staff experiences in a UK specialist palliative care setting.	International Journal of Palliative Nursing	Study - qualitative study to explore clinician experiences of discussing PPD with palliative care patients
Finlay, Ilora	2006	Crossing the 'bright line' - difficult decisions at the end of life	Clinical Medicine	Lecture

Firn, Janice; Preston, Nancy; Walshe, Catherine	2016	What are the views of hospital-based generalist palliative care professionals on what facilitates or hinders collaboration with in-patient specialist palliative care teams? A systematically constructed narrative synthesis.	Palliative Medicine	Study - narrative synthesis to assess the existing evidence of inpatient generalist palliative care providers perceptions of what facilitates or hinders collaboration with hospital-based specialist palliative care teams
Ford-Dunn S; Smith A; Quin J	2006	Management of diabetes during the last days of life: attitudes of consultant diabetologists and consultant palliative care physicians in the UK	Palliative Medicine	Study - questionnaire of attitudes of consultant diabetologists and consultant palliative care physicians
Frank RK	2009	Shared decision making and its role in end of life care.	British Journal of Nursing	Study - literature review aiming to identify the extent to which shared decision making currently exists during end of life care
Fritz, Zoë; Cork, Nick; Dodd, Alex; Malyon, Alexandra	2014	PROFESSIONAL ISSUES. DNACPR decisions: challenging and changing practice in the wake of the Tracey judgment.	Clinical Medicine	Review
Furber, L.; Cox, K.; Murphy, R.; Steward, W.	2013	Investigating communication in cancer consultations: what can be learned from doctor and patient accounts of their experience?	European Journal of Cancer Care	Study - ethnography
Gadoud, Amy; Adcock, Yousef; Jones, Lesley; Koon, Sim; Johnson, Miriam	2013	"It's not all doom and gloom": perceptions of medical students talking to hospice patients.	Journal of palliative medicine	Study - qualitative exploring the views and experience of medical students
Gadoud, Amy; Johnson, Miriam	2011	Recognizing advanced disease	British Journal of Hospital Medicine	Clinical guidance

Gadoud, Amy; Jones, Lesley; Johnson, Miriam; Adcock, Yousef; Arolker, Milind; Barnes, Julia	2012	Medical students talking to hospice patients.	The clinical teacher	Review
Gardiner C; Gott M; Ingleton C	2012	Factors supporting good partnership working between generalist and specialist palliative care services: a systematic review.	British Journal of General Practice	Study - Systematic review exploring factors that support partnership working between specialist and generalist palliative care providers
Gardiner C; Gott M; Small N; Payne S; Seamark D; Barnes S; Halpin D; Ruse C	2009	Living with advanced chronic obstructive pulmonary disease: patients [sic] concerns regarding death and dying.	Palliative Medicine	Study - qualitative exploration of experiences of patients with COPD
Gardiner, Clare; Cobb, Mark; Gott, Merryn; Ingleton, Christine	2011	Barriers to providing palliative care for older people in acute hospitals.	Age and ageing	Study - qualitative exploring perspectives of health professionals regarding barriers to optimal palliative care for older people in acute hospitals
Gardiner, Clare; Gott, Merryn; Payne, Sheila; Small, Neil; Barnes, Sarah; Halpin, David; Ruse, Charlotte; Seamark, David	2010	Exploring the care needs of patients with advanced COPD: An overview of the literature	Respiratory Medicine	Review
Gardiner, Clare; Harrison, Madeleine; Ryan, Tony; Jones, Amanda	2013	Provision of palliative and end-of-life care in stroke units: A qualitative study	Palliative Medicine	Study - qualitative exploration perspectives of health professionals regarding the provision of end-of-life care in UK stroke units
Gaveras, Eleni Margareta; Kristiansen, Maria; Worth, Allison; Irshad, Tasneem; Sheikh, Aziz	2014	Social support for South Asian Muslim parents with life-limiting illness living in Scotland: a multiperspective qualitative study	Bmj Open	Study - qualitative, secondary analysis exploring experiences of social support

Gibbins J; Smith GS; Forbes K	2009	Lesson of the week: life saving treatment for a 'palliative care' patient.	BMJ: British Medical Journal (Overseas & Retired Doctors Edition)	Case Study
Gibbins, J.; McCoubrie, R.; Maher, J.; Wee, B.; Forbes, K.	2010	Recognizing that it is part and parcel of what they do: teaching palliative care to medical students in the UK	Palliative Medicine	Study - mixed methods questionnaire + interviews to explore views and experiences of coordinators of palliative care in different UK medical schools
Gibbins, Jane; McCoubrie, Rachel; Forbes, Karen	2011	Why are newly qualified doctors unprepared to care for patients at the end of life?	Medical Education	Study - qualitative study of perceptions of newly qualified doctors
Gibbins, Jane; McCoubrie, Rachel; Maher, Jane; Forbes, Karen	2009	Incorporating palliative care into undergraduate curricula: lessons for curriculum development	Medical Education	Study - qualitative exploration factors that help or hinder incorporation of palliative care teaching at undergraduate level in the UJ
Gillett, Karen; O'Neill, Bernadette; Bloomfield, Jacqueline G.	2016	Factors influencing the development of end-of-life communication skills: A focus group study of nursing and medical students	Nurse Education Today	Study - qualitative exploration of factors influencing the development of end-of-life communication skills by nursing and medical students
Glogowska, Margaret; Simmonds, Rosemary; McLachlan, Sarah; Cramer, Helen; Sanders, Tom; Johnson, Rachel; Kadam, Umesh T.; Lasserson, Daniel S.; Purdy, Sarah	2016	"Sometimes we can't fix things": a qualitative study of health care professionals' perceptions of end of life care for patients with heart failure	Bmc Palliative Care	Study - qualitative study
GMC	2010	Treatment and Care Towards the End of Life: Good Practice in Decision Making		Clinical guideline

Goggin, Mary	2012	Parents perceptions of withdrawal of life support treatment to newborn infants	Early Human Development	Clinical guidance
Goodman, Claire; Evans, Catherine; Wilcock, Jane; Froggatt, Katherine; Drennan, Vari; Sampson, Elizabeth; Blanchard, Martin; Bissett, Maggie; Iliffe, Steve	2010	End of life care for community dwelling older people with dementia: an integrated review	International Journal of Geriatric Psychiatry	Study - integrated review
Gott, M.; Small, Neil; Barnes, Sarah; Payne, Sheila; Seamark, David	2008	Older people's views of a good death in heart failure: Implications for palliative care provision	Social Science & Medicine	Review
Gott, Merryn; Barnes, Sarah; Parker, Chris; Payne, Sheila; Seamark, David; Gariballa, Salah; Small, Neil	2007	Dying trajectories in heart failure	Palliative Medicine	Study - prospective study of heart failure patients exploring trajectories in heart failure
Gott, Merryn; Seymour, Jane; Ingleton, Christine; Gardiner, Clare; Bellamy, Gary	2012	'That's part of everybody's job': the perspectives of health care staff in England and New Zealand on the meaning and remit of palliative care	Palliative Medicine	Study - qualitative exploration of understand of and perceived roles
Grunfeld, E. A.; Maher, E. J.; Browne, S.; Ward, P.; Young, T.; Vivat, B.; Walker, G.; Wilson, C.; Potts, H. W.; Westcombe, A. M.; Richards, M. A.; Ramirez, A. J.	2006	Advanced breast cancer patients' perceptions of decision making for palliative chemotherapy	Journal of Clinical Oncology	Study - qualitative, examining perceptions of information they received
Gunatilake, Samal; Brims, Fraser J. H.; Fogg, Carole; Lawrie, Iain; Maskell, Nick; Forbes, Karen; Rahman, Najib; Morris, Steve; Ogollah, Reuben; Gerry, Stephen; Peake, Mick; Darlison, Liz; Chauhan, Anoop J.	2014	A multicentre non-blinded randomised controlled trial to assess the impact of regular early specialist symptom control treatment on quality of life in malignant mesothelioma (RESPECT-MESO): study protocol for a randomised controlled trial	Trials	Study - protocol for a RCT
Gupta, Neelam; Harrop, Emily; Lapwood, Susie; Shefler, Alison	2013	Journey from Pediatric Intensive Care to Palliative Care	Journal of Palliative Medicine	Study - Retrospective case note review

Hain, Richard; Devins, Mary; Hastings, Richard; Noyes, Jayne	2013	Paediatric palliative care: development and pilot study of a 'Directory' of life-limiting conditions	Bmc Palliative Care	Study - Retrospective case note review and development of directory
Hanratty, Barbara; Hibbert, Derek; Mair, Frances; May, Carl; Ward, Chris; Corcoran, Ged; Capewell, Simon; Litva, Andrea	2006	Doctors' understanding of palliative care	Palliative Medicine	Study - qualitative exploration of understanding of palliative care
Harding, Richard	2013	TERMINAL ILLNESS DEBATE How to hope for the best while planning for the worst in terminal illness	Bmj-British Medical Journal	Letter to Editor
Harding, Richard; Selman, Lucy; Beynon, Teresa; Hodson, Fiona; Coady, Elaine; Read, Caroline; Walton, Michael; Gibbs, Louise; Higginson, Irene J.	2008	Meeting the communication and information needs of chronic heart failure patients	Journal of Pain and Symptom Management	Study - qualitative aiming to generate guidance of appropriate information for provision of palliative care to patients with CHF
Harrison, Jennifer K.; Clipsham, Laura E.; Cooke, Caroline M.; Warwick, Graham; Burton, James O.	2015	Establishing a Supportive Care Register Improves End-of-Life Care for Patients with Advanced Chronic Kidney Disease	Nephron	Study - comparison observational study to assess impact of introducing a supportive care register on the end-of-life care for patients with advanced CKD
Harrop, Emily; Edwards, Clare	2013	How and when to refer a child for specialist paediatric palliative care.	Archives of Disease in Childhood -- Education & Practice Edition	Clinical guidance
Hayle, Catherine; Coventry, Peter A.; Gomm, Stephanie; Caress, Ann-Louise	2013	Understanding the experience of patients with chronic obstructive pulmonary disease who access specialist palliative care: A qualitative study	Palliative Medicine	Study - qualitative, to evaluate experiences of patients with COPD who access specialist palliative care
Hicks, Fiona	2012	Avoiding emergency stops in end of life care.	Clinical Medicine	Editorial

Higginson, Irene J.	2012	Palliative care Outcome Scale (POS) - Home		Patient questionnaire
Higginson, Irene J.; Evans, Catherine J.	2010	What Is the Evidence That Palliative Care Teams Improve Outcomes for Cancer Patients and Their Families?	Cancer Journal	Study - systematic review, aiming to address: Do SPCTS achieve their aims and improve outcomes for patients with advanced cancer and their caregivers
Hill, Loreena; McIlfatrick, Sonja; Taylor, Brian; Dixon, Lana; Harbinson, Mark; Fitzsimons, Donna	2015	Patients' perception of implantable cardioverter defibrillator deactivation at the end of life	Palliative Medicine	Study - systematic narrative review aiming to evaluate the evidence on patients perception of ICD deactivation at end of life
Hodgkinson, Sarah; Ruegger, Josh; Field-Smith, Antonia; Latchem, Susan; Ahmedzai, Sam H.	2016	Care of dying adults in the last days of life	Clinical Medicine	Clinical guidance
Holland, C. L.; Bowker, L. K.; Myint, P. K.	2013	Barriers to involving older people in their resuscitation decisions: the primary-secondary care mismatch highlights the potential role of general practitioners.	International journal of clinical practice	Study - questionnaire to assess current clinical practice in primary and secondary care and perceived barriers to patient involvement in resuscitations decisions
Horn, Ruth	2014	"I don't need my patients' opinion to withdraw treatment": patient preferences at the end-of-life and physician attitudes towards advance directives in England and France.	Medicine, health care, and philosophy	Study - qualitative exploring English and French physicians moral perspectives and attitudes towards end-of-life decisions when patients lack capacity to make decisions for themselves

Horridge, Karen A.	2015	Advance Care Planning: practicalities, legalities, complexities and controversies	Archives of Disease in Childhood	Review
Howell, D. A.; Wang, H.-I.; Roman, E.; Smith, A. G.; Patmore, R.; Johnson, M. J.; Garry, A. C.; Howard, M. R.	2015	Variations in specialist palliative care referrals: findings from a population-based patient cohort of acute myeloid leukaemia, diffuse large B-cell lymphoma and myeloma	Bmj Supportive & Palliative Care	Study - prospective data collection to develop and implement a methodology for capturing complete haematological malignancy pathway data and use it to identify variations in SPC referrals
Howell, Debra A.; Shellens, Rhiannon; Roman, Eve; Garry, Anne C.; Patmore, Russell; Howard, Martin R.	2011	Haematological malignancy: are patients appropriately referred for specialist palliative and hospice care? A systematic review and meta-analysis of published data	Palliative Medicine	Study - systematic review and meta-analysis to examine the proportion of patients with haematological malignancies that received any form of specialist palliative or hospice care
Hunt, Katherine J.; Shlomo, Natalie; Addington-Hall, Julia	2014	End-of-Life Care and Preferences for Place of Death among the Oldest Old: Results of a Population-Based Survey Using VOICES-Short Form	Journal of Palliative Medicine	Study - survey aiming to explore experiences of EOLC among the oldest old and determine reported preference for preference for place of death
Hussain, Jamilla A.; Flemming, Kate; Murtagh, Fliss E. M.; Johnson, Miriam J.	2015	Patient and Health Care Professional Decision-Making to Commence and Withdraw from Renal Dialysis: A Systematic Review of Qualitative Research	Clinical Journal of the American Society of Nephrology	Study - systematic review to explore how and why different factors mediate the choices about dialysis treatment
Hyde, Val; Skirton, Heather; Richardson, Janet	2011	Palliative day care: A qualitative study of service users' experiences in the United Kingdom	Nursing & Health Sciences	Study - qualitative study exploring experiences of services users in palliative day care

Ingleton, Christine; Gardiner, Clare; Seymour, Jane E.; Richards, Naomi; Gott, Merryn	2013	Exploring education and training needs among the palliative care workforce.	BMJ supportive & palliative care	Study - mixed methods to explore perceptions of healthcare professionals regarding their training and educational needs
Ismail, Yasmin; Shorthose, Kate; Nightingale, Angus K.	2015	Trainee experiences of delivering end-of-life care in heart failure: key findings of a national survey.	British Journal of Cardiology	Study - questionnaire to evaluate the confidence of trainees in managing end-of-life issues
Jack B; Hillier V; Williams A; Oldham J	2006	Improving cancer patients' pain: the impact of the hospital specialist palliative care team.	European Journal of Cancer Care	Study - non-equivalent control group design comparing outcomes for patients receiving specialist hospital palliative care and those receiving traditional care
Janssen, Anna L.; MacLeod, Roderick D.	2010	What does care mean? Perceptions of people approaching the end of life	Palliative & Supportive Care	Study - qualitative exploring nature of medical care from perspective of people approaching the end of life
Jarrett, N.; Porter, K.; Davis, C.; Addington-Hall, J.; Duke, S.; Corner, J.; Lathlean, J.	2015	The networks of care surrounding cancer palliative care patients	Bmj Supportive & Palliative Care	Study - qualitative exploring nature and extent of the networks of care surrounding patients with cancer palliative care needs
Johnson, Miriam J.	2007	Management of end stage cardiac failure	Postgraduate Medical Journal	Review
Johnson, Miriam J.	2010	Extending palliative care to patients with heart failure	British Journal of Hospital Medicine	Clinical guidance

Johnston, Sheila; Noble, Helen	2012	Factors influencing patients with stage 5 chronic kidney disease to opt for conservative management: a practitioner research study	Journal of Clinical Nursing	Study - qualitative exploring decision-making experiences of patients with stage 5 CKD when opting for conservative management of their renal failure
Joseph S; Chapman S; Regnard C	2010	The difference between general care planning and advance care planning.	End of Life Care Journal	Clinical guidance
Kernohan, W. G.; Hasson, F.; Hutchinson, P.; Cochrane, B.	2006	Patient satisfaction with hospice day care	Supportive Care in Cancer	Study - questionnaire exploring patient satisfaction
Kite S	2010	Advance care planning.	Clinical Medicine	Clinical guidance
Kydd, Angela; Sharp, Barbara	2016	Palliative care and dementia-A time and place?	Maturitas	Review
Lawrence, Vanessa; Samsi, Kritika; Murray, Joanna; Harari, Danielle; Banerjee, Sube	2011	Dying well with dementia: qualitative examination of end-of-life care	British Journal of Psychiatry	Study - qualitative aiming to define good end-of-life care for people with dementia and identify how it can be delivered across care settings in the UK
LeBon, B.; Fisher, S.	2011	Case report: Maintaining and withdrawing long-term invasive ventilation in a patient with MND/ALS in a home setting	Palliative Medicine	Case study
Linklater, Gordon T.; Bowden, Joanna; Pope, Lyndsey; McFatter, Fiona; Hutchison, Stephen M. W.; Carragher, Pat J.; Walley, John; Fallon, Marie; Murray, Scott A.	2014	Developing learning outcomes for medical students and foundation doctors in palliative care: a national consensus-seeking initiative in Scotland.	Medical teacher	Description of consensus agreement exercise outline learning outcomes of undergraduate palliative care

Low, Catherine; Finucane, Anne; Mason, Bruce; Spiller, Juliet	2014	Palliative care staff's perceptions of do not attempt cardiopulmonary resuscitation discussions.	International Journal of Palliative Nursing	Study - qualitative aiming to explore clinician experiences of discussing DNACPR decisions with people
Lowton, Karen	2009	'A bed in the middle of nowhere': Parents' meanings of place of death for adults with cystic fibrosis	Social Science & Medicine	Study - qualitative, parents experiences
Lund, Susi; Richardson, Alison; May, Carl	2015	Barriers to Advance Care Planning at the End of Life: An Explanatory Systematic Review of Implementation Studies	Plos One	Study - systematic review to investigate barriers and facilitators to the implementation of ACPs
Mahmood-Yousuf K; Munday D; King N; Dale J	2008	Interprofessional relationships and communication in primary palliative care: impact of the Gold Standards Framework.	British Journal of General Practice	Study - qualitative interviews aiming to investigate the extent to which the GSF influences interprofessional relationships and communication and to compare GPs and nurses experiences
Mason, Bruce; Buckingham, Susan; Finucane, Anne; Hutchison, Peter; Kendall, Marilyn; McCutcheon, Hazel; Porteous, Lorna; Murray, Scott A.	2015	Improving primary palliative care in Scotland: lessons from a mixed methods study	Bmc Family Practice	Study - mixed methods aiming to understand impact of Palliative Care Directed Enhanced Service
Mason, Bruce; Epiphaniou, Eleni; Nanton, Veronica; Donaldson, Anne; Shipman, Cathy; Daveson, Barbara A.; Harding, Richard; Higginson, Irene; Munday, Dan; Barclay, Stephen; Boyd, Kirsty; Dale, Jeremy; Kendall, Marilyn; Worth, Allison; Murray, Scott A.	2013	Coordination of care for individuals with advanced progressive conditions: a multi-site ethnographic and serial interview study	British Journal of General Practice	Study - mixed methods aiming to identify how care is coordinated in generalist settings for individuals with advanced progressive conditions in the last year of life

McAdoo, Stephen P.; Brown, Edwina A.; Chesser, Alistair M.; Farrington, Ken; Salisbury, Emma M.	2012	Measuring the quality of end of life management in patients with advanced kidney disease: results from the pan-Thames renal audit group	Nephrology Dialysis Transplantation	Study - retrospective case note review aiming to evaluate EOLC relating to deaths of patients on dialysis
McCulloch, Renee; Comac, Maggie; Craig, Finella	2008	Paediatric palliative care: Coming of age in oncology?	European Journal of Cancer	Review
McLaughlin, Dorry; Barr, Owen; McIlfatrick, Sonja; McConkey, Roy	2015	Service user perspectives on palliative care education for health and social care professionals supporting people with learning disabilities	Bmj Supportive & Palliative Care	Study - qualitative aiming to elicit view of peole with learning disabilities and their family carers concerning palliative care to inform healthcare professional education and training
Metaxa, Victoria; Lavrentieva, Athina	2015	End-of-life decisions in Burn Intensive Care Units - An International Survey	Burns	Study - survey aiming to evaluate physician beliefs, values, considerations and difficulties in end-of-life decisions in burn ICUs
Miller, Sarah; Dorman, Saskie	2014	Resuscitation decisions for patients dying in the community: a qualitative interview study of general practitioner perspectives.	Palliative medicine	Study - qualitative interview study aiming to investigate how GPs think and feel about making and communicating DNACPR decisions for patients dying in the community
Miller, Sophie J.; Desai, Nishita; Pattison, Natalie; Droney, Joanne M.; King, Angela; Farquhar-Smith, Paul; Gruber, Pascale C.	2015	Quality of transition to end-of-life care for cancer patients in the intensive care unit	Annals of Intensive Care	Study - mixed methods exploring quallity of transition to EOLC

Minto, Fiona; Strickland, Karen	2011	Anticipating emotion: a qualitative study of advance care planning in the community setting.	International journal of palliative nursing	Study - qualitative aiming to determine factors that assist or hinder primary care health professionals having these discussions
Mitchell, Helen; Noble, Simon; Finlay, Ilora; Nelson, Annmarie	2013	Defining the palliative care patient: its challenges and implications for service delivery.	BMJ supportive & palliative care	Study - qualitative exploring GPs views of what defines a palliative care patient in the context of identifying clinical service needs
Mitchell, Oscar J. L.	2013	SCRAPPING OF LIVERPOOL CARE PATHWAY We need more care, less pathway at the end of life	Bmj-British Medical Journal	Letter to Editor
Mitchell, Sarah; Dale, Jeremy	2015	Advance Care Planning in palliative care: A qualitative investigation into the perspective of Paediatric Intensive Care Unit staff.	Palliative Medicine	Study - qualitative to explore the experiences of senior medical and nursing staff regarding the challenges associated with ACP in relation to children and young people with life-limiting illnesses in the paediatric ICU
Munday, Daniel F.; Maher, E. Jane	2008	Informed consent and palliative chemotherapy	British Medical Journal	Editorial
Murray, Scott A.; Kok, Jaan Yang	2008	Internationally, it is time to bridge the gap between primary and secondary healthcare services for the dying.	Annals of the Academy of Medicine, Singapore	Commentary
Murray-Brown, Fay; Curtis, Matt; Gibbins, Jane	2015	Survey of Foundation Year 1 doctors caring for the dying; what do they see, do and need to perform this role, following removal of the Liverpool Care Pathway?	Palliative Medicine	Study - (research letter) about survey of FY1 doctors caring for the dying

Murtagh, F. E. M.; Thorns, A.	2006	Evaluation and ethical review of a tool to explore patient preferences for information and involvement in decision making	Journal of Medical Ethics	Study - before and after comparing satisfaction with amount of information given
National Institute for Health and Clinical Excellence	2015	Care of dying adults in the last days of life | NICE		Clinical guideline
National Institute for Health and Clinical Excellence	2016	End of life care for infants, children and young people | Guidance and guidelines | NICE		Clinical guideline
National Institute for Health and Clinical Excellence	2011	End of life care for adults | Guidance and guidelines | NICE		Clinical guideline
Nava, S.; Sturani, C.; Hartl, S.; Magni, G.; Ciontu, M.; Corrado, A.; Simonds, A.	2007	End-of-life decision-making in respiratory intermediate care units: a European survey.	The European respiratory journal	Study - questionnaire to assess end-of-life practices in patients admitted to European respiratory intermediate care units and HDUs
Neilson, Sue J.; Kai, Joe; Macarthur, Christine; Greenfield, Sheila M.	2011	Caring for children dying from cancer at home: a qualitative study of the experience of primary care practitioners.	Family practice	Study - qualitative study of experience of primary care practitioners
NHS Scotland	2015	NHS Scotland Realistic medicine		Government white paper
Noble, Sir; Nelson, A.; Finlay, I. G.	2008	Factors influencing hospice thromboprophylaxis policy: a qualitative study	Palliative Medicine	Study - qualitative exploring factors influencing thromboprophylaxis practice
O'Brien, Mary; Jack, Barbara	2010	Barriers to dying at home: the impact of poor co-ordination of community service provision for patients with cancer	Health & Social Care in the Community	Study - qualitative, focus groups with DNs and community specialist palliative care nurses
Owen, Ray; Jeffrey, David	2008	Communication: Common challenging scenarios in cancer care	European Journal of Cancer	Clinical guidance

Papadopoulou, C.; Kotronoulas, G.; Simpson, M.; Maguire, R.	2011	Supportive Care Needs of Patients With Lung Cancer - a Systematic Review of the Literature	European Journal of Cancer	Study - systematic review to determine the supportive care needs of people with lung cancer and explore trends and gaps in the assessment of these needs emerging from this literature
Papavasiliou, Evangelia S.; Brearley, Sarah G.; Seymour, Jane E.; Brown, Jayne; Payne, Sheila A.	2013	From Sedation to Continuous Sedation Until Death: How Has the Conceptual Basis of Sedation in End-of-Life Care Changed Over Time?	Journal of Pain and Symptom Management	Study - evidence review to address and account for the conceptual debate over the terminology and definitions ascribed to sedation at the end fo life over time
Parsons, Carole; McCorry, Noleen; Murphy, Kevin; Byrne, Stephen; O'Sullivan, David; O'Mahony, Denis; Passmore, Peter; Patterson, Susan; Hughes, Carmel	2014	Assessment of factors that influence physician decision making regarding medication use in patients with dementia at the end of life.	International Journal of Geriatric Psychiatry	Study - survey aiming to evaluate the extent to which patient related factors and physicians country of practice influence decisions regarding medication use in patients with end stage dementia
Pattison, Natalie; Carr, Susan M.; Turnock, Chris; Dolan, Shelley	2013	'Viewing in slow motion': patients', families', nurses' and doctors' perspectives on end-of-life care in critical care.	Journal of clinical nursing	study - qualitative exploring the meaning of end-of-life care for critically ill cancer patients, families, oncologists, palliative specialists, critical care consultants and nurses

Pattison, Natalie; O'Gara, Geraldine; Wigmore, Timothy	2015	Negotiating Transitions: Involvement of Critical Care Outreach Teams in End-of-Life Decision Making	American Journal of Critical Care	Study - retrospective qualitative analysis
Pino, Marco; Parry, Ruth; Land, Victoria; Faull, Christina; Feathers, Luke; Seymour, Jane	2016	Engaging Terminally Ill Patients in End of Life Talk: How Experienced Palliative Medicine Doctors Navigate the Dilemma of Promoting Discussions about Dying	Plos One	Study - qualitative to examine how palliative medicine doctors engage patients in end-of-life talk
Pitcher, David; Soar, Jasmeet; Hogg, Karen; Linker, Nicholas; Chapman, Simon; Beattie, James M.; Jones, Sue; George, Robert; McComb, Janet; Glancy, James; Patterson, Gordon; Turner, Sheila; Hampshire, Susan; Lockey, Andrew; Baker, Tracey; Mitchell, Sarah	2016	Cardiovascular implanted electronic devices in people towards the end of life, during cardiopulmonary resuscitation and after death: guidance from the Resuscitation Council (UK), British Cardiovascular Society and National Council for Palliative Care	Heart	Clinical guidance
Pivodic, Lara; Harding, Richard; Calanzani, Natalia; McCrone, Paul; Hall, Sue; Deliens, Luc; Higginson, Irene J.; Gomes, Barbara	2016	Home care by general practitioners for cancer patients in the last 3 months of life: An epidemiological study of quality and associated factors	Palliative Medicine	Study - epidemiological study of quality and associated factors
Pontin, David; Jordan, Nikki	2013	Issues in prognostication for hospital specialist palliative care doctors and nurses: A qualitative inquiry.	Palliative Medicine	Study - qualitative, exploration of hospital palliative specialists experience of prognostication
Preston, Harriet; Fineberg, Iris Cohen; Callagher, Pauline; Mitchell, Douglas J.	2012	The Preferred Priorities for Care document in Motor Neurone Disease: Views of bereaved relatives and carers	Palliative Medicine	Study - qualitative, examining MND patients' bereaved relatives' experiences of using preferred priorities for care document
Price, Sophie; Schofield, Susie	2015	How do junior doctors in the UK learn to provide end of life care: a qualitative evaluation of postgraduate education.	BMC palliative care	Study - qualitative evaluation of trainees working in general medicine

Price, Susanna; Haxby, Elizabeth	2013	Managing futility in critically ill patients with cardiac disease.	Nature Reviews Cardiology	Review
Pringle, Jan; Johnston, Bridget; Buchanan, Deans	2015	Dignity and patient-centred care for people with palliative care needs in the acute hospital setting: A systematic review	Palliative Medicine	Study - systematic review aiming to examine international evidence relating to dignity and person-centred care for people with palliative care needs in the acute hospital setting
Puckey, Michele; Bush, Andrew	2011	"Passage to Paradise" Ethics and end-of-life decisions in children	Paediatric Respiratory Reviews	Review
Pugh, E. J.; Song, R.; Whittaker, V.; Blenkinsopp, J.	2009	A profile of the belief system and attitudes to end-of-life decisions of senior clinicians working in a National Health Service Hospital in the United Kingdom.	Palliative medicine	Study - questionnaire exploring belief system of consultants, nurse key works and registrars and their attitudes to decisions which commonly must be taken when caring for individuals who are dying
Raphael, Claire; Kanagaratnam, Prapa; Francis, Darrel P.	2010	Further Barriers to Conversations About Deactivation of Implantable Cardioverter-Defibrillators	Journal of the American College of Cardiology	Letter to Editor
Reid, Colette; Gibbins, Jane; Bloor, Sophia; Burcombe, Melanie; McCoubrie, Rachel; Forbes, Karen	2015	Healthcare professionals' perspectives on delivering end-of-life care within acute hospital trusts: a qualitative study	Bmj Supportive & Palliative Care	Study - qualitative exploring healthcare professionals perspectives on delivering end-of-life care
Richfield, Edward W.; Jones, Edward J. S.; Alty, Jane E.	2013	Palliative care for Parkinson's disease: A summary of the evidence and future directions	Palliative Medicine	Review

Robertson KA; Hutchison SMV	2009	Assessment of iron status and the role for iron-replacement therapy in anaemic cancer patients under the care of a specialist palliative care unit.	Palliative Medicine	Study - observational study of iron deficiency anaemia, prevalence and benefits of iron replacement therapy and the prevalence of side effects
Robinson, Frances; Cupples, Margaret; Corrigan, Mairead	2007	Implementing a resuscitation policy for patients at the end of life in an acute hospital setting: qualitative study.	Palliative medicine	Study - qualitative, exploring attitudes and experiences of doctors and nurses regarding CPR for patients with end stage illness in an acute hospital
Robinson, Louise; Dickinson, Claire; Bamford, Claire; Clark, Alexa; Hughes, Julian; Exley, Catherine	2013	A qualitative study: Professionals' experiences of advance care planning in dementia and palliative care, 'a good idea in theory but ...'	Palliative Medicine	Study - qualitative exploring professionals experiences on the implementation of advance care planning in dementia and palliative care
Royal College of General Practitioners	2016	Palliative and End of Life Care Toolkit		Clinical guideline
Royal College of General Practitioners	2011	GSF Prognostic Indicator Guidance		Clinical guidance
Royal College of Physicians	2016	End of Life Care Audit – Dying in Hospital: National report for England 2016	RCP London	Clinical audit
Royal College of Physicians	2009	Concise Guidance to Good Practice - Number 12 Advance Care Planning National Guidelines		Clinical guideline
Rueda, José-Ramón; Solà, Ivan; Pascual, Antonio; Subirana Casacuberta, Mireia	2011	Non-invasive interventions for improving well-being and quality of life in patients with lung cancer	Cochrane Database of Systematic Reviews	Study - systematic review assessing effectiveness of non-invasive interventions delivered by healthcare professionals

Ryan, Tony; Gardiner, Clare; Bellamy, Gary; Gott, Merryn; Ingleton, Christine	2012	Barriers and facilitators to the receipt of palliative care for people with dementia: The views of medical and nursing staff	Palliative Medicine	Study - qualitative exploring experiences of health care practitioners working in palliative care
Ryan, Tony; Ingleton, Christine; Gardiner, Clare; Parker, Chris; Gott, Merryn; Noble, Bill	2013	Symptom burden, palliative care need and predictors of physical and psychological discomfort in two UK hospitals		Study - surveys exploring the extent of symptom burden in two large UK hospitals
Sampson, Elizabeth L.; Jones, Louise; Thune-Boyle, Ingela C. V.; Kukkastenvehmas, Riitta; King, Michael; Leurent, Baptiste; Tookman, Adrian; Blanchard, Martin R.	2011	Palliative assessment and advance care planning in severe dementia: An exploratory randomized controlled trial of a complex intervention	Palliative Medicine	Study - RCT
Schildmann, Jan; Tan, Jacinta; Salloch, Sabine; Vollmann, Jochen	2013	"Well, I Think There Is Great Variation...": A Qualitative Study of Oncologists' Experiences and Views Regarding Medical Criteria and Other Factors Relevant to Treatment Decisions in Advanced Cancer	Oncologist	Study - qualitative exploring medical oncologists experiences with advanced cancer
Scott, Kirsty	2010	Incidence of sudden, unexpected death in a specialist palliative care inpatient setting	Palliative Medicine	Study - research letter, retrospective case note review
Scottish Government	2008	Living and Dying Well: A National Action Plan for Palliative and End of Life Care in Scotland		Government white paper
Scottish Intercollegiate Guidelines Network	2014	SIGN 139 - Care of deteriorating patients		Clinical guideline
Scottish Partnership for Palliative Care	2014	Scottish Palliative Care Guidelines - Rapid Transfer Home in the Last Days of Life		Clinical guideline
Scottish Partnership for Palliative Care	2014	Scottish Palliative Care Guidelines - Care in the Last Days of Life		Clinical guideline
Scottish Partnership for Palliative Care	2014	Scottish Palliative Care Guidelines - Out of Hours Handover		Clinical guideline

Seale, C.	2006	National survey of end-of-life decisions made by UK medical practitioners	Palliative Medicine	Study - survey of UK medical practitioners to assess doctors view on the adequacy of current UK law
Seale, Clive	2010	The role of doctors' religious faith and ethnicity in taking ethically controversial decisions during end-of-life care.	Journal of medical ethics	Study - survey of UK medical practitioners reporting on their last patient who died
Seamark, David; Blake, Susan; Brearley, Sarah G.; Milligan, Christine; Thomas, Carol; Turner, Mary; Wang, Xu; Payne, Sheila	2014	Dying at home: a qualitative study of family carers' views of support provided by GPs community staff	British Journal of General Practice	Study - qualitative, aiming to elicit family carers views about the community support that made death at home possible
Seamark, David; Blake, Susan; Seamark, Clare; Hyland, Michael E.; Greaves, Colin; Pinnuck, Margaret; Ward, David; Hawkins, Adam; Halpin, David	2012	Is hospitalisation for COPD an opportunity for advance care planning? A qualitative study	Primary Care Respiratory Journal	Study - qualitative, aiming to examine whether an admission to hospital for an exacerbation of COPD is an opportunity for ACP
Selman, Lucy Ellen; Beattie, James M.; Murtagh, Fliss E.; Higginson, Irene J.	2009	Palliative care: Based on neither diagnosis nor prognosis, but patient and family need. Commentary on Chattoo and Atkin	Social Science & Medicine	Commentary
Seymour, Jane E.; French, Jeff; Richardson, Eve	2010	Spotlight: Palliative Care Beyond Cancer Dying matters: let's talk about it	British Medical Journal	Commentary
Seymour, Jane E.; Janssens, Rien; Broeckaert, Bert	2007	Relieving suffering at the end of life: Practitioners' perspectives on palliative sedation from three European countries	Social Science & Medicine	Study - qualitative, aiming to learn about clinicians and academic researchers understandings and experiences of palliative sedation for managing suffering at the end of life

Sharp, Tim; Moran, Emily; Kuhn, Isla; Barclay, Stephen	2013	Do the elderly have a voice? Advance care planning discussions with frail and older individuals: a systematic literature review and narrative synthesis	British Journal of General Practice	Study - systematic literature review investigating the attitudes of the public and healthcare professionals to ACPs with frail and older people
Sheard, Laura; Prout, Hayley; Dowding, Dawn; Noble, Simon; Watt, Ian; Maraveyas, Anthony; Johnson, Miriam	2012	The ethical decisions UK doctors make regarding advanced cancer patients at the end of life--the perceived (in) appropriateness of anticoagulation for venous thromboembolism: a qualitative study.	BMC medical ethics	Study - qualitative study exploring barriers for doctors in the UK when diagnosing and treating advanced cancer patients with VTE
Shipman, Cathy; Gysels, Marjolein; White, Patrick; Worth, Allison; Murray, Scott A.; Barclay, Stephen; Forrest, Sarah; Shepherd, Jonathan; Dale, Jeremy; Dewar, Steve; Peters, Marilyn; White, Suzanne; Richardson, Alison; Lorenz, Karl; Koffman, Jonathan; Higginson, Irene J.	2008	Improving generalist end of life care: national consultation with practitioners, commissioners, academics, and service user groups	British Medical Journal	Report of consultation
Sivell, Stephanie; Lidstone, Victoria; Taubert, Mark; Thompson, Catherine; Nelson, Annmarie	2015	Identifying the key elements of an education package to up-skill multidisciplinary adult specialist palliative care teams caring for young adults with life-limiting conditions: an online Delphi study	Bmj Supportive & Palliative Care	Study -modified online Delphi to collate expert opinion
Sleeman, Katherine E.; Collis, Emily	2013	Caring for a dying patient in hospital	Bmj-British Medical Journal	Clinical guidance

Smith, L. J.; Vergnaud, S.; Wright, H.; Bates, C.	2012	Death and the Respiratory Physician: Challenges to Providing Optimal End-of-Life Care by Generalists	Thorax	Study - (abstract) questionnaire investigating experiences, beliefs and attitudes of doctors in a district general hospital towards end of life care, focusing on issues relevant to respiratory patients
Spence, A.; Hasson, F.; Waldron, M.; Kernohan, W. G.; McLaughlin, D.; Watson, B.; Cochrane, B.; Marley, A. M.	2009	Professionals delivering palliative care to people with COPD: qualitative study	Palliative Medicine	Study - qualitative exploring facilitators and barriers to delivery of end of life care for COPD patients
Sprung, Charles L.; Carmel, Sara; Sjokvist, Peter; Baras, Mario; Cohen, Simon L.; Maia, Paulo; Beishuizen, Albertus; Nalos, Daniel; Novak, Ivan; Svantesson, Mia; Benbenishty, Julie; Henderson, Beverly	2007	Attitudes of European physicians, nurses, patients, and families regarding end-of-life decisions: the ETHICATT study.	Intensive care medicine	Study - questionnaire evaluating attitudes of Europeans regarding end-of-life decisions
St Ledger, Una; Begley, Ann; Reid, Joanne; Prior, Lindsay; McAuley, Danny; Blackwood, Bronagh	2013	Moral distress in end-of-life care in the intensive care unit.	Journal of advanced nursing	Study - (protocol) narrative inquiry case study to explore moral distress in relatives doctors and nurses in EOLC decision-making in adult ITU
Steel, A.; Goldring, J.	2015	End-of-life care in patients with chronic obstructive pulmonary disease.	British Journal of Hospital Medicine (17508460)	Clinical guidance
Stone, Paddy; Gwilliam, Bridget; Keeley, Vaughan; Todd, Chris; Gittins, Matthew; Kelly, Laura; Barclay, Stephen; Roberts, Chris	2012	Patients' reports or clinicians' assessments: which are better for prognosticating?	BMJ supportive & palliative care	Study - prognostic models developed, and compared between groups

Subramaniam, Sivakumar; Thorns, Andrew; Ridout, Martin; Thirukkumaran, Thiru; Osborne, Thomas Richard	2015	Accuracy of prognosis prediction by PPI in hospice inpatients with cancer: a multi-centre prospective study	Bmj Supportive & Palliative Care	Study - use of palliative prognostic index
Taylor, Francesca; Taylor, Celia; Baharani, Jyoti; Nicholas, Johann; Combes, Gill	2016	Integrating emotional and psychological support into the end-stage renal disease pathway: a protocol for mixed methods research to identify patients' lower-level support needs and how these can most effectively be addressed	BMC Nephrology	Study - (protocol) mixed methods, to determine what, when, and how support for patients with lower-level emotional and psychological problems should be integrated into the end-stage renal disease pathway
Thorns A	2010	Ethical and legal issues in end-of-life care.	Clinical Medicine	Review
Todd, A.; Nazar, H.; Pearson, S.; Andrew, I.; Baker, L.; Husband, A.	2014	Inappropriate prescribing in patients accessing specialist palliative day care services	International Journal of Clinical Pharmacy	Study - modified Delphi to reach consensus of medication appropriateness
Todd, Adam; Holmes, Holly; Pearson, Sallie; Hughes, Carmel; Andrew, Inga; Baker, Lisa; Husband, Andy	2016	'I don't think I'd be frightened if the statins went': a phenomenological qualitative study exploring medicines use in palliative care patients, carers and healthcare professionals	Bmc Palliative Care	Study - qualitative, exploring the lived experience of patients, carers and healthcare professionals in the context of medication use in life-limiting illness
Tomlinson, Kim; Barker, Stephanie; Soden, Katie	2012	What are cancer patients' experiences and preferences for the provision of written information in the palliative care setting? A focus group study	Palliative Medicine	Study - qualitative, to identify the experiences and wishes of patients known to a specialist palliative care service

Tuffrey-Wijne I; McEnhill L; Curfs L; Hollins S	2007	Palliative care provision for people with intellectual disabilities: interviews with specialist palliative care professionals in London.	Palliative Medicine	Study - qualitative exploring issues and difficulties arising for palliative care staff in providing care for people with intellectual disabilities
Tuffrey-Wijne I; Whelton R; Curfs L; Hollins S	2008	Palliative care provision for people with intellectual disabilities: a questionnaire survey of specialist palliative care professionals.	Palliative Medicine	Study - questionnaire to gain insight into the current use of palliative care services by people with ID in London
Tunnicliffe KR; Mackay A	2011	Tips for GP trainees working in palliative care.	British Journal of General Practice	Clinical guidance
Turner-Stokes, Lynne; Sykes, Nigel; Silber, Eli	2008	Long-term neurological conditions: management at the inter-face between neurology, rehabilitation and palliative care	Clinical Medicine	Clinical guidance
Tyrer, F.; Williams, M.; Feathers, L.; Faull, C.; Baker, I.	2009	Factors that influence decisions about cardiopulmonary resuscitation: the views of doctors and medical students.	Postgraduate medical journal	Study - qualitative, investigating factors that influence decisions about CPR
University of Edinburgh	2013	SPICT – SPICT		Clinical guideline
van de Luijtgaarden, Moniek W. M.; Noordzij, Marlies; van Biesen, Wim; Couchoud, Cecile; Cancarini, Giovanni; Bos, Willem-Jan W.; Dekker, Friedo W.; Gorriz, Jose L.; Iatrou, Christos; Wanner, Christoph; Finne, Patrik; Stojceva-Taneva, Olivera; Cala, Svjetlana; Stel, Vianda S.; Tomson, Charles; Jager, Kitty J.	2013	Conservative care in Europe-nephrologists' experience with the decision not to start renal replacement therapy	Nephrology Dialysis Transplantation	Study - survey to nephrologists inquiring how often renal replacement therapy was not started in 2009

van der Cammen, Tischa J. M.; Rajkumar, Chakravarthi; Onder, Graziano; Sterke, Carolyn S.; Petrovic, Mirko	2014	Drug cessation in complex older adults: time for action	Age and Ageing	Study - literature review to identify the effects and effectiveness of drug cessation on falls, delirium and cognitive impairment.
van Vliet, Liesbeth M.; Gao, Wei; DiFrancesco, Daniel; Crosby, Vincent; Wilcock, Andrew; Byrne, Anthony; Al-Chalabi, Ammar; Chaudhuri, K. Ray; Evans, Catherine; Silber, Eli; Young, Carolyn; Malik, Farida; Quibell, Rachel; Higginson, Irene J.	2016	How integrated are neurology and palliative care services? Results of a multicentre mapping exercise	Bmc Neurology	Study - mapping of current level of connections and integration between these services
Walshe C; Todd C; Caress A	2008	Judgements about fellow professionals and the management of patients receiving palliative care in primary care: a qualitative study.	British Journal of General Practice	Study - qualitative, exploring influences on referrals within general and specialist community palliative care services
Walshe, C.; Caress, A.; Chew-Graham, C.; Todd, C.	2008	Implementation and impact of the Gold Standards Framework in community palliative care: a qualitative study of three primary care trusts	Palliative Medicine	Study - qualitative exploring anticipation and adoption of the GSF within 3 primary care trusts
Walshe, Catherine; Chew-Graham, Carolyn; Todd, Chris; Caress, Ann	2008	What influences referrals within community palliative care services? A qualitative case study	Social Science & Medicine	Study - qualitative, aiming to investigate the influences on referral decisions made within community palliative care services
Walshe, Catherine; Todd, Chris; Caress, Ann; Chew-Graham, Carolyn	2009	Patterns of Access to Community Palliative Care Services: A Literature Review	Journal of Pain and Symptom Management	Study - literature review

Wee, Bee; Barclay, Stephen	2012	High-quality care should be available at all times at end of life.	Guidelines in Practice	Commentary
White, Clare; McMullan, Damien; Doyle, Julie	2009	"Now that You Mention it, Doctor ... '': Symptom Reporting and the Need for Systematic Questioning in a Specialist Palliative Care Unit	Journal of Palliative Medicine	Study - retrospective case notes review
Wiese, Michele; Stancliffe, Roger J.; Balandin, Susan; Howarth, Glennys; Dew, Angela	2012	End-of-Life Care and Dying: Issues Raised by Staff Supporting Older People with Intellectual Disability in Community Living Services	Journal of Applied Research in Intellectual Disabilities	Study - qualitative aiming to explore the current status of end-of-life care and dying of people with intellectual disability based on the experiences of staff in community living services
Wilkinson, Dominic James	2011	A life worth giving? The threshold for permissible withdrawal of life support from disabled newborn infants.	The American journal of bioethics : AJOB	Review
Williams, Nia; Dunford, Charlotte; Knowles, Alice; Warner, James	2007	Public attitudes to life-sustaining treatments and euthanasia in dementia	International Journal of Geriatric Psychiatry	Study - survey to elicit views of the general public on euthanasia and life-sustaining treatments in the face of dementia
Wilson E; Cox K	2007	Community palliative care development: evaluating the role and impact of a general practitioner with a special interest in palliative medicine.	Palliative Medicine	Study - mixed methods evaluating the role of GP with special interest in palliative care
Wilson E; Seymour JE; Perkins P	2010	Working with the Mental Capacity Act: findings from specialist palliative and neurological care settings.	Palliative Medicine	Study - qualitative aiming to gain an understanding of knowledge of the MCA, capacity and documentation among HCPs

Wilson, F.; Gott, M.; Ingleton, C.	2013	Perceived risks around choice and decision making at end-of-life: A literature review	Palliative Medicine	Study - integrative literature review aiming to explore how perceptions of risk may inform decision-making processes at the end of life
Wolff, A.; Browne, J.; Whitehouse, W. P.	2011	Personal resuscitation plans and end of life planning for children with disability and life-limiting/life-threatening conditions	Archives of Disease in Childhood-Education and Practice Edition	Clinical guidance
Woolcock, S. C.; De Soyza, J.; Crockett, R.; Day, M.; Fisher, A. J.; Lordan, J.; MacGowan, G.; Corris, P. A.	2014	The Role of Specialist Palliative Care Services in the Management of Patients with Pulmonary Arterial Hypertension; a Review of Current Practice	Thorax	Study - (abstract) retrospective case note review aiming to outline current practice
Worth, Allison; Irshad, Tasneem; Bhopal, Raj; Brown, Duncan; Lawton, Julia; Grant, Elizabeth; Murray, Scott; Kendall, Marilyn; Adam, James; Gardee, Rafik; Sheikh, Aziz	2009	Vulnerability and access to care for South Asian Sikh and Muslim patients with life limiting illness in Scotland: prospective longitudinal qualitative study	British Medical Journal	Study - prospective, longitudinal, qualitative, aiming to examine the care experiences of patients with life limiting illness and their families and to understand the reasons for any difficulties with access to services and how these might be overcome
Yang, Grace M.; Ewing, Gail; Booth, Sara	2012	What is the role of specialist palliative care in an acute hospital setting? A qualitative study exploring views of patients and carers	Palliative Medicine	Study - qualitative, exploring patient and carer perspectives of the role of palliative care in the acute hospital setting with patients not imminently dying

Young, J. A.; Waugh, L.; McPhillips, G.; Levack, P.; Thompson, A. M.	2013	Palliative care for patients with gastrointestinal cancer dying under surgical care: A case for acute palliative care units?	Surgeon-Journal of the Royal Colleges of Surgeons of Edinburgh and Ireland	Study - retrospective review of notes aiming to examine end of life care in patients dying of GI cancer in Scottish hospital surgical wards
Zacharias, Hannah; Raw, Janet; Nunn, Anne; Parsons, Sharon; Johnson, Miriam	2011	Is there a role for subcutaneous furosemide in the community and hospice management of end-stage heart failure?	Palliative Medicine	Study - retrospective review of notes

Appendix 7. Peer-reviewed published methodology article

S.P. Qureshi, K. Rankin. (2019). Junior-to-junior research interviews as method for clinical practitioner-researchers. *Advances in Medical Education and Practice*, 10: 127-137

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